Promoting collaboration between users and health professionals: the experience of Maternity Services Liaison Committees

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Abstract

The inclusion of user representatives in committees and groups alongside health professionals is one of several ways of involving users in the planning and monitoring of health services. However, there have been reports of barriers to the involvement of users in such groups and very little is understood about the processes that take place and the factors which promote effectiveness.

This study addresses this shortfall in relation to a specific type of user involvement forum in maternity services - the Maternity Services Liaison Committee (MSLC). MSLCs are attached to hospital trusts or health authorities and bring together health professionals and local users to plan and monitor local maternity services. The study is a qualitative assessment of a sample of eight MSLCs using a combination of observation and interview methods. It investigates the structure and work of MSLCs, the way members participate, and the meaning and value of MSLCs to members, in order to establish the effectiveness of MSLCs and potential for improvement.

The committees were found to have a limited direct impact on maternity services. Arguably their greatest influence was in promoting collaboration between constituent groups and the accountability of health professionals. The impact of MSLCs and the extent to which users were involved were limited by factors to do with the structure and processes of the committees. MSLCs could be improved to some extent through changes to these, but improvement beyond a certain point would be difficult to achieve because the problems reflect fundamental issues to do with the structure of the health service and the way MSLCs were set up, the high degree of professional control over MSLC activity and health care in general, and characteristics of users. These findings have implications for the effectiveness of other forums for user involvement presently being implemented in the health service.

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Chapter one: Introduction

The inclusion of user representatives in committees and groups alongside health professionals is one of several ways of involving users in the planning and monitoring of health services. This type of involvement contrasts with many consultation exercises where health professionals take account of users' views but where users do not participate directly in the decision making process. The UK government has demonstrated commitment to this method of user involvement by including lay membership on primary care groups and in a variety of new committees introduced in the recent NHS reforms (HMSO 2000).

However, despite the apparent commitment to this form of involvement and the number of forums that do exist, there have been reports of barriers to the adequate involvement of users through this mechanism. Some forums, such as primary care groups and research advisory groups, have avoided or delayed appointing lay members (Smith and Dickson 1998; NHS Executive 1998a). Where users have been included, there have been concerns about tokenism. The role of user members has not been clarified and there has been no support and no structure for user members to work in (Rigge 1994; Liberati 1997; NHS Executive 1998a; Kelson and Redpath 1996; Fisher 1999; Johns 1999). User members have found it difficult to participate because of a lack of knowledge, skills and resources (Brownlea 1987; Beresford and Croft 1993; Hanley et al 2000). These obstacles are the result of the way the health service is structured and organised; the way user involvement has developed in an ad hoc way; and the high level of professional dominance that exists in the health service. The sources of information on the problems associated with these committees and groups have been surveys and anecdotal reports. There has been little or no systematic study of how the groups work and how members interact.

Maternity Services Liaison Committees (MSLCs) were first introduced in 1982 and are one of the most longstanding forums for user involvement in the NHS in England and Wales. They are accountable to health authorities and / or hospital trusts and there is at least one such committee in every English health district. MSLCs were set up in response to concerns about perinatal mortality rates and the wide variation in these around the country and between social groups (Lewison 1994). They were to bring together all the professionals involved in maternity care along with lay representatives to improve standards (Department of Health 1984). They were expected to improve communication and co-operation between professionals and draw on the experience of users. The introduction of MSLCs was the first initiative within the NHS which represented an explicit commitment to involving user representatives in discussions about service provision alongside health professionals.

Several government reports have confirmed the importance of MSLCs and provided advice on how they should develop (House of Commons Health Committee 1992; Department of Health 1993a). They contained a combination of vague, but ambitious advice that MSLCs should be influential in maternity service development, and specific recommendations in relation to improving user representation. The most recent recommendations were launched by the NHS Executive *Changing Childbirth* Implementation Team in November 1996 (NHS Executive 1996). These provide advice on structure, procedure and remit and aim to strengthen user involvement and the strategic role of MSLCs.

MSLCs were slow to include lay representation, although most now have at least one user member. Many have recently changed from professional to lay chairship. There is very little information on what MSLCs actually do, but there is some indication that

many committees are not involved in some of the planning and monitoring activities recommended in the NHS Executive guidelines (NHS Executive 1996).

Research into the effectiveness of MSLCs has been limited to surveys of structure and members' views (Joule 1995; Garcia 1987; Royal College of Midwives 1992; Newburn 1992; Gready et al 1995; Fletcher et al 1997). These surveys have demonstrated wide variation in the structure of MSLCs and widespread concerns about their effectiveness. User respondents reported that their committees were dominated by health care professionals and showed only limited commitment to involving users. In addition, they did not feel confident about challenging other members of the committee. The author became interested in MSLCs and how they promote user involvement whilst working on an evaluation of a project run by Camden and Islington MSLC which aimed to promote evidence-based policy and practice in specific aspects of obstetric and maternity care. The project prompted audit activity and reviews of policy in local hospital units, but had little direct impact on policies or practices that were at odds with the research findings (Berrow et al 1997; Humphrey and Berrow 2000). There were varying degrees of disagreement between the health authority representatives and user members running the project and the consultants and midwives whose practice was under review. It became clear that they had different perspectives on how research findings should inform practice and not everyone was committed to the idea that users should be involved in discussions about clinical care.

The expectation behind the MSLC initiative is that a multidisciplinary environment which brings together users and all those involved with maternity care will have the capacity to improve maternity services and will allow users to participate in the process. To date there has been no systematic study of how effective MSLCs are as a forum for this purpose. The surveys mentioned above have identified some of the

problems but have provided little help in understanding the work of MSLCs and the nature of the interaction between users and health professionals. In addition, these surveys focused mostly on the views of user members and were conducted by user organisations - there is little written from the perspective of health professionals.

The study reported here aims to address this gap through an in-depth qualitative assessment of a sample of MSLCs. By investigating the structure and work of MSLCs, the way members participate and interact, and the meaning and value of MSLCs to those involved, the thesis will establish the effectiveness of MSLCs at improving maternity services and involving users in this endeavour. It will establish the mechanisms by which MSLCs have an influence in maternity services and the factors that determine the extent of their impact. It will explore the extent and nature of user involvement and identify the factors that influence this. User involvement through MSLCs will then be assessed against various models of user involvement. The implications of the findings for the future development of MSLCs and user involvement in forums in general in the health service will be examined. MSLCs are likely to be a valuable model for problems that will be experienced in the growing number of other comparable forums involving users in the health service.

Structure of the thesis

Background chapters

Chapters two, three and four provide background information on maternity services, MSLCs and user involvement in the health service. Chapter two provides an overview of the history and development of maternity services in the UK and looks at the current service from the perspectives of users and health professionals. The aim of this chapter is to promote an appreciation of the activity, motivations and relationship

issues that form the context for this study. Chapter three describes the history and development of MSLCs, including the initiatives aiming to improve their effectiveness. It reviews the research on MSLC effectiveness and identifies the progress MSLCs have made and the challenges they face. Chapter four provides an overview of the history and development of user involvement in the health service in Britain. It describes the various mechanisms that exist for user involvement and the barriers that limit their effectiveness. It provides an overall assessment of user involvement in the health service and identifies the main factors that have shaped its development.

Methodology

Chapter five begins by exploring the rationale behind the qualitative approach taken in the study. Subsequent sections describe the sampling criteria used to identify the study MSLCs and interview respondents, and the methods used to collect observation and interview data. The approach to analysis of observation and interview data is then described and this is followed by a discussion of the trustworthiness of qualitative research and how this issue has been addressed in this study. The characteristics of the study MSLCs and interview respondents are then presented.

Findings (chapters six to nine)

Chapters six, seven and eight use findings from fieldwork observations and committee documents to describe and analyse the structure of the study MSLCs, the nature of their work, and the ways in which members participated. Chapter six describes their membership, formal aims and procedures of the committees; chapter seven identifies MSLC topics and develops a typology of activity in relation to these; and chapter eight establishes the ways in which users and health professionals participated in the work of the MSLC, features of the interaction between them, and the factors that influenced this. In each case, the chapter assesses the findings against policy expectations and

draws out the significant factors that appear to have an impact on what MSLCs can achieve in maternity services and the extent to which users are involved.

Chapter nine reports the findings of the interviews with MSLC members. The aim of the interviews was to identify the meaning and value of the MSLC to those involved. The investigation of meaning includes the background of the members and their motivation for involvement, as well as their views on the purpose of the committee. The investigation of value looks at members' views on the achievements, shortcomings and overall worth of their committees.

Assessment and evaluation (chapters ten to twelve)

The three final chapters bring together the findings of the study to answer the fundamental questions of the thesis. Chapter ten establishes the impact of the MSLCs on maternity services. It identifies the mechanisms by which the MSLCs in the study were able to influence maternity services and the conditions which affected the extent of their impact. The chapter then assesses the overall impact of the MSLCs and the extent to which the findings of the study can be generalised to all MSLCs. Chapter eleven identifies the variables which determined the nature and effectiveness of user involvement in the study MSLCs and looks at the potential for user involvement to improve given the challenges they face. Chapter twelve establishes the extent to which MSLCs gave users a meaningful role in decision making and examines the extent to which the findings can be transferred to other forums for user involvement in the health service. This is followed by an analysis of whether user inclusion in committees and groups can be considered a worthwhile endeavour given the constraints that have been identified and a discussion of the policy implications of the study findings.

Chapter two:

The history and development of maternity services in England

This chapter provides an overview of the history and development of maternity services over the past hundred years. It describes how maternity care changed from a community based service provided by midwives and general practitioners to a hospital obstetric led service, and how women and midwives became increasingly dissatisfied. It shows how the interests of women and midwives came together with the interests of government to bring about a sea change in maternity policy that put midwives back at the centre of maternity care. Women were to be offered choices of care and carer, have control over their treatment and receive continuity of care. The chapter concludes by looking at the practical and professional barriers to the implementation of this policy and assesses the developments from the perspectives of users, midwives, consultants and GPs.

The history and development of maternity services in England

Main changes in the course of the twentieth century

The nature of maternity care in England has changed substantially in the past hundred years. This has been reflected in the rising trend in hospitalisation for childbirth. The percentage of women giving birth in hospital was less than 15% before 1927, had risen to 54% by the end of World War II, and to 91% by 1972 (Oakley 1984). In 1970 the Peel Committee advocated a 100% hospitalisation rate for childbirth. For the next twenty years, recommendations of government and professional groups promoted an increase in obstetric involvement in childbirth and the number of obstetricians in

hospitals increased (Social Services Committee 1980). The percentage of women giving birth in hospital rose to 99% and remained roughly at this level throughout the 1990s (Rivett 1998). Intervention during childbirth also increased. The caesarean rate had risen from 1% in 1970 to 20% by 1993 (Francome et al 1993). The rate for induction of labour rose from 13% in 1958 to 21% in 1994 (Tew 1995; RCOG 1996); and the number of women having episiotomies at least doubled between the same years (Tew 1995; Graham 1997).

The roles of midwives and doctors have changed accordingly. In the early part of the twentieth century when maternity care was community based, the main carers were midwives and general practitioners. As hospitalisation increased, obstetricians took more responsibility and their involvement in routine care increased. Maternity care became more fragmented and women no longer received the continuity of care experienced by earlier generations. Midwives lost their professional autonomy as they became subsumed into hospital hierarchies where power rested with doctors (Harcombe 1999) and GPs became less involved with childbirth. In 1965 GPs delivered 50% of all births, but by 1993 this had fallen to below 13% (Zander and Chamberlain 1999).

The response of women

Research into women's experiences of pregnancy and childbirth from the 1970s onwards has demonstrated widespread dissatisfaction with the impersonal nature of maternity care, lack of choice over type of care, lack of control over the process of childbirth, and poor continuity of care (Reid and McIlwaine 1980; Green et al 1990; Hutton 1994; Kenny et al 1993). A lack of information at all stages of antenatal,

intrapartum and postnatal care was found to contribute to low levels of satisfaction (Green et al 1990; Fleissig 1990).

Many consumer organisations have been set up in recent decades to provide support to women which was considered lacking in the health service and to promote the needs and interests of women at a national level. These organisations are concerned with a diverse set of issues associated with pregnancy and obstetrics (Reid 1997). Some, such as the Association for Improvements in Maternity Services (AIMS), focus on maternity care in general while others, such as the Stillbirth and Neonatal Deaths Society (SANDS), focus on specific problems experienced by women. The two groups most influential in challenging the sense of powerlessness among women have been the Association for Improvements in the Maternity Services and the National Childbirth Trust (NCT).

Consumers have not been the sole critics of maternity care. Sociologists and feminist writers in the 1980s described the harm inflicted on women through obstetric intervention (Donnison 1988; Oakley 1980, 1984; Tew 1995). They showed how childbirth had become redefined as a medical condition and was no longer considered by doctors to be a natural process. They explained how the focus on childbirth as a medical problem was promoted and reinforced by the provision of maternity care within hospitals, places which were usually concerned with disease. This medicalisation of childbirth was seen as destructive for women as it led to an erosion of self-confidence and ultimately to a reduction in the ability to give birth without medical intervention. Research indicated that powerlessness during childbirth could cause psychological damage to women (Oakley 1984). In addition, several authors questioned the evidence that had been put forward in support of hospitalisation and medical intervention (Richards 1975; Oakley 1980; Macintyre 1977). The statistician Margaret Tew found

that mortality and morbidity rates had decreased long before the move to hospital care (Tew 1995).

The government was aware of women's concerns. In 1979 it had commissioned Ann Cartwright to conduct a survey of women's experiences of maternity care and this demonstrated the problems women experienced with hospitalisation and active management of labour (Sandall 1997a). The government's response to these concerns was to examine maternity care and suggest improvements (Department of Health 1982, 1984, 1985). However, the recommendations focused on the need to improve communication between carers and women and did not address the fundamental structure and process of maternity care.

The response of midwives

Towards the end of the twentieth century midwives became increasingly critical of the high rate of medical intervention in uncomplicated pregnancy and the erosion of their expertise. They were frustrated by the limited and subservient role they had acquired in relation to obstetricians and the diminished opportunities they had to form relationships with women (Walker 1976). In spite of the fact that midwives have independent practitioner status in law, there has been concern that they have become obstetric nurses and do not in practice carry the responsibility for normal births that befits their skills (Walker 1976; Robinson 1985).

Changes to the mainstream policy ideas of midwifery reflected these concerns. The Association of Radical Midwifery (ARM) was set up in 1976 as a study and support group for student midwives who had concerns about the eroding role of midwives. Ten years later its ideas had been accepted by mainstream professional organisations

including the Royal College of Midwives (RCM) and were on the political agenda. Both organisations proposed changes to maternity services which would address the problems as both midwives and women saw them (Flint 1986; RCM 1987). They recommended midwifery led care as a way of promoting choice and continuity of care for women and greater job satisfaction for midwives. In the late 1980s and early 1990s a small number of team midwifery schemes were introduced by innovative midwifery managers (Flint et al 1989).

The government's review of maternity services

In 1991 the government set up a Health Select Committee to review maternity services. The committee's findings were a striking contrast to previous government reports. The committee accepted that hospital birth was not necessarily the safest option and emphasised the central role that could be taken by midwives in the care of most women during pregnancy and childbirth (House of Commons Health Committee 1992). Subsequent work initiated by the government assessed the present availability of team midwifery (Wraight et al 1993) and of midwifery-led and GP-led units (Department of Health 1993b).

In response to the findings of the Select Committee, the government established an Expert Group to review and develop maternity policy. This group consisted of midwives, obstetricians, GPs, paediatricians and lay representatives. It endorsed continuity of care and women-centred care and suggested midwives should have a greater role in securing this for uncomplicated pregnancies. In 1993 the document *Changing Childbirth* detailed the action to be taken locally to meet the new requirements (Department of Health 1993a). The principles were incorporated into the Patients' Charter for maternity services (Department of Health 1994).

The ambitions of users and of midwives provided some impetus for the review of maternity services, but the government was also independently motivated by its own interests. User groups had been vocal about their criticisms of maternity services for many years but this was the first time they had been properly represented in the actual development of policy. By the time of the review of maternity services, promoting user involvement and choice had become one arm of the government's strategy to challenge what it saw as unacceptable medical control over health service resources. It found support for a reduction in medical control over maternity services in the findings of systematic reviews which questioned the effectiveness of some obstetric interventions (Chalmers et al 1989), its own research which demonstrated the feasibility of team midwifery and midwifery led units (Department of Health 1993b; Wraight et al 1993), and work by others that showed low intervention care was just as safe as obstetric led care (Mugford 1990).

The impact of *Changing Childbirth*

The *Changing Childbirth* document was launched in 1993 and welcomed by midwives and consumer groups. Regions, districts and trusts were required by the NHS Executive to review their maternity services and develop a strategy to implement the document's recommendations (NHS Executive 1994). Implementation was to be evaluated within the next five years by progress in meeting targets in key areas. These reflected the proposed shift from obstetric led care to midwifery led care. One target was that at least 30% of women should have the midwife as the lead professional. Others were that at least 75% of women should know the person who cares for them during delivery and that every woman should know one midwife who ensures continuity of her midwifery care.

Progress in implementing the requirements of *Changing Childbirth* has been slow. A survey of eight regional health authorities by the National Association of Health Authorities and Trusts (NAHAT 1996) showed up problems achieving a shift from consultant led to midwifery led care and in providing continuity of care. By 1995, only 20% of women had the midwife as the lead professional and only 15% knew the person caring for them at delivery.

The Audit Commission's report on maternity services in 1997 (which came out during the observation period of the study reported in this thesis) identified significant shortfalls in meeting some of the *Changing Childbirth* indicators of success. Its survey of women established that there had been improvements in communication between health care professionals and users, but that women were still not being offered choices of maternity care and were not adequately involved in decisions relating to their care (Audit Commission 1997).

What constitutes continuity of care has not been well defined. Various models of midwifery care now exist (RCM 1999). Some midwives work in groups or teams which provide antenatal and postnatal care for women in a defined geographical area. Some of these midwives also go into hospital to deliver the babies of women in the team's caseload. A minority of midwives have personal caseloads and provide one-to-one care through antenatal, intrapartum and postnatal stages. Others work in either the community or hospital along traditional lines (Sandall 1995). In a national survey of midwives, nearly half reported that they worked in a team (Sandall 1997b). However, many of the groups were so large that, while the system was nominally referred to as team midwifery, these 'teams' did not allow women to get to know their midwives any more than had been possible under the previous system (Gready et al 1995; Sandall 1997c). There has been concern that *Changing Childbirth* has not been adequately

resourced and as a consequence has raised expectations that cannot be met (Lewis 1997; Robinson 1996).

There appears to be a danger that focusing on promoting continuity of carer ignores other factors that women find just as important. A study comparing the effects of shared and personal midwifery caseloads found that friendliness and support, good communication and involvement in decision making were more important determinants of women's satisfaction than personal continuity of carer (Morgan et al 1998).

The extent to which *Changing Childbirth* is successful in the longer term remains to be seen. However, its ability to address some fundamental problems has been thrown into doubt and there is some scepticism as to whether the new policy can lead to a reduction in intervention in childbirth (Cowie and Floyd 1999). There has been a rise in the number of technologies and interventions used by midwives in 'normal' or low risk pregnancies. For instance, in many units it is normal practice during labour to monitor the fetal heartbeat continually using a cardiotocograph. The over sensitivity of this technique leads to unnecessary inductions and caesarean sections (Cowie and Floyd 1999). For this and a variety of other reasons caesarean rates are still rising.

There is also some doubt that the policy can improve outcomes for women whose problems go beyond a lack of choice and continuity of care. *Changing Childbirth* does not address social factors such as poverty and nutrition that influence access to maternity care and outcomes for the health of mother and baby (Cresswell 1993; Stephen 1993). The report of the working group (Department of Health 1993a) acknowledged the importance of these factors in exacerbating problems women experience with pregnancy and childbirth but subsequent policy failed to address them.

The user, midwifery and medical perspective on maternity services

This section describes the response of users and health care professionals to the *Changing Childbirth* initiative and the issues they currently face.

The user perspective

Consumer groups supported and contributed to the *Changing Childbirth* policy. It was hoped that the policy would address the disempowerment of women that was associated with obstetric control of childbirth. However, there is concern that in practice the interests of midwives are overriding those of women. The danger is that in promoting their independence from the medical profession midwives are establishing themselves as specialists in maternity care rather than as partners with women (Harcombe 1999). There is fear that a profession aiming to increase its autonomy and sphere of practice is losing sight of the ideology of continuity of care (Sandall 1997a).

There are of course women who do not reject obstetric intervention and are not committed to the idea that natural childbirth is best. They embrace the benefits of modern technology and obstetrics and see caesarean section as a choice that should be available (Bennet 1999). To those women involved in the struggle for women-centred maternity care and a reduction in medical intervention this may reflect the extent to which childbearing women have become disempowered in society and have been encouraged to have unjustified faith in the benefits of obstetric technology.

The midwifery perspective

In general, midwives supported *Changing Childbirth* and have been facing the challenge of implementing its requirements. This has necessitated substantial reorganisation of midwives and changes to their responsibilities and working patterns. There continue to be many practical and professional problems.

Some studies have shown that providing continuity of care leads to an increase in professional autonomy and job satisfaction (Hundley et al 1995), but others have reported an increase in stress, the potential for burn-out, and concern among midwives about conflict with doctors (Watson 1990; Currell 1990). There is some indication that midwifery dissatisfaction is due to compromises made on the grounds of cost and convenience. Midwives working in big teams with large caseloads were found to be disillusioned because they were unable to provide continuity and get to know users (Todd et al 1998) whereas midwives who had personal caseloads and control over their own work patterns had a greater sense of accomplishment from their work (Sandall 1997c). Most midwives do not carry personal caseloads and work in large teams and therefore do not reap the benefits that might offset the disadvantages of long on call hours and disruption to family and social life. In addition, the new systems were expected to promote the professional standing of midwives, but there have been reports of widespread deskilling and downgrading (Lewis 1997).

Continuity of care is harder for midwifery managers to implement where midwives wish to work part time, require maternity leave or prefer to work traditional shifts in hospital. There has been concern that midwives requiring more flexible employment are being sidelined for their apparent lack of commitment to midwifery and this has led to calls from within the profession to ensure that the service promotes flexible working and

appreciates the contribution that can be made by midwives who have children (Warwick 1996; Sandall 1995).

The new system presents midwives with professional challenges which some do not feel adequately prepared for. As a result of the erosion of the midwifery role many midwives do not have the skills or confidence to provide women with appropriate choices. The rigidity with which guidelines and policies are implemented in hospitals presents an additional organisational barrier (Judge 1997). Midwives are faced with the task of balancing rules and procedures enshrined in their midwifery codes of conduct (UKCC 1993, 1994) with the need to be flexible and accommodate the requirements of individual women.

In addition, not all midwives are committed to a change in their role. In a survey in 1987 half the midwifery respondents were happy with the traditional system and did not want this changed. Those who had trained as nurses before becoming midwives were less keen on the idea of midwifery led care than those who had vocationally trained as midwives (Weitz 1987). Some midwives have questioned the widespread relevance of increasing choice for women and promoting women-centred care. In a survey of heads of midwifery, many respondents did not think the majority of women saw choice as an important feature of maternity care, and felt the concept was only applicable to a well informed, well motivated and educated minority (Bradshaw and Bradshaw 1997).

Midwives are presently facing challenges to do with the reoganisation of the health service arising from the NHS Reforms of 1998 (Department of Health 1998). From a practical point of view they are concerned that the new organisational boundaries do not damage communication between midwives working in different locations (Dimond

1999). On a more strategic level they are facing the challenge of ensuring that the midwifery perspective is well represented in Primary Care Groups (Kaufman 1998). There are also likely to be changes to the way the profession is governed (Kaufman 1998). The Royal College of Midwifery's position is that the current legislation should be reformed to enhance the autonomy of midwives.

The obstetric perspective

The Royal College of Obstetricians and Gynaecologists was resistant to some of the changes recommended in the *Changing Childbirth* document. It issued a press release stating that the report was recommending major alterations to current practice without an objective review of the available evidence (Dunlop 1993). It did not agree with the exclusion of obstetricians from normal pregnancy and expressed concern that midwifery would become isolated from obstetrics. The Royal College was also concerned that the new policy would lead to an increase in home birth, an option they did not consider to be as safe as birth in hospital.

The response of some obstetricians was more positive and emphasised that the changes built upon existing developments (Anderson 1993). Some obstetricians accepted the principle of midwifery led care but did not feel there was sufficient trial evidence to show that midwifery led care achieved perinatal outcomes and satisfaction for women comparable to those from obstetric led care (Turnball et al 1994; Drife 1995). They thought that midwifery led care was inappropriate for many women. A study in 1993 found that midwifery led care was in practice only appropriate for a small percentage of women. Half of the women in the study were assessed to be unsuitable for midwifery led care in the first place and half of those initially accepted were

subsequently transferred to specialist obstetric care because of complications (MacVicar et al 1993).

Obstetricians are currently facing challenges on two fronts. The present focus on promoting evidence-based medicine in the health service has been particularly pronounced in maternity and obstetric care. The Cochrane Centre provides evidence for and against obstetric procedures and makes recommendations for change and the profession has been required by its Royal College to review practices in the light of this information (The Cochrane Pregnancy and Childbirth Database 1997; RCOG 1993). The public has had access to this evidence and as a consequence the profession has been open to public scrutiny in a way that has not happened before. A second issue obstetricians face is the rise in caesarean section rates. The Audit Commission found that many caesarean sections were not medically indicated and recommended that action should be taken to reduce caesarean rates (Department of Health 1998). Obstetricians are in the position of having to defend themselves against what they see as unfair criticism. They have complained that requirements to reduce the caesarean rate show no appreciation of the need to practice defensive medicine in order to avoid the risk of litigation nor of the fact that more women are asking for caesareans. Experience in the United States leads them to be sceptical about the benefits that would accrue from a reduction in caesareans. A study there found that efforts to reduce the rate led to an increase in the incidence of ruptured uterus, particularly in those women who attempted a vaginal delivery after having a caesarean for a previous delivery (Gottlieb 1999).

The General Practitioner perspective

The implementation of *Changing Childbirth* had the potential to change the role of the GP in maternity care and the relationship between GPs and midwives who provide care for women on their lists. There was some resistance among GPs to the implementation of midwifery led care because it would lead to a reduction in their provision of antenatal care (Stephen 1993; Smith 1993), which they enjoy and for which they are remunerated. Surveys of GPs' attitudes to the development of midwifery group practice found that while they were generally positive about the quality of care provided by midwives, they felt that there was poor communication with midwives (Fenwick et al 1998; Farquhar et al 2000). In addition, many GPs were unclear about their own role in maternity care and felt that they were seeing women too few times (Fenwick et al 1998).

Changing Childbirth provided support for greater GP involvement in maternity care in that it advocated greater GP participation in intrapartum care (Department of Health 1993a). When the new policy was implemented there was only a small 'hard core' of 10-15% of GPs who still provided intra-partum care in hospital or at home (Brown 1994), although there were regional variations with up to half involved in this way in some areas (Baker 1992; Smith 1994). The low participation of GPs has been attributed to their perceived lack of expertise, fear of litigation, changes in the organisation of out of hours cover, unacceptable encroachment on off duty hours and inadequate remuneration (Zander and Chamberlain 1999; Frain et al 1996). In addition, GPs have felt discouraged by the attitudes of consultant obstetricians and midwives (Smith 1996). A survey in 1996 found that 35% of consultant obstetricians did not think GP led intrapartum care for low risk women was as safe as consultant led care. Well over half (69%) did not think women would want GP care. In addition, many

GPs are equivocal in their approach to home birth and are not prepared to give cover for home birth (Davies et al 1996).

Those GPs who are interested in providing intrapartum care find it difficult to obtain the necessary teaching and experience as only a small proportion of consultants provide this (Frain et al 1996) and there are now very few independent GP units (Zander and Chamberlain 1999).

Conclusion

The provision of maternity services has changed substantially over the last century. The change has been in the direction of increased intervention and obstetric supervision. In recent years there has been a drive to promote midwifery led care and this has led to a reorganisation of midwives. There are shortfalls in the extent to which new arrangements provide women with choice, continuity of care and control over their care. How successful the policy will be in the longer term remains to be seen but there are many practical and professional barriers, not least the conflicting interests of users, midwives, obstetricians and GPs.

Chapter three:

The history and development of Maternity Services Liaison Committees

This chapter provides an overview of the history and development of MSLCs in England and Wales. It describes the policy that led to the setting up of MSLCs and subsequent guidance on how they should be developed. It charts the development of MSLCs to the present day and reviews the evidence relating to their effectiveness. The various initiatives that have set out to support user representatives and improve MSLCs are then described.

Policy developments

MSLCs are multidisciplinary groups that bring together representatives of healthcare professionals, health authorities and local users for the purpose of planning and monitoring maternity services. The establishment of MSLCs was recommended by the Maternity Services Advisory Committee in 1982 (Department of Health 1982). This committee had been set up by the government in response to concern about variation in perinatal mortality rates around the country and between social groups (Lewison 1994) and also in part in response to the large number of complaints made by women about the care they received in hospital (Department of Health 1985). The committee reviewed maternity services and produced a three-volume report describing the areas within antenatal, intrapartum and postnatal care that needed to be improved (Department of Health 1982, 1984, 1985).

The new MSLCs were to promote improvements on a local level and to ensure that local users had a voice in this process. They were to be set up by district health

authorities with the purpose of ensuring 'that the best possible standard of maternity care is available for all mothers' (Department of Health 1984). MSLCs were expected to improve the communication and co-operation between health professionals and to draw on the experience of users. They were intended to have a development and monitoring function, which would involve 'the agreement of generally applicable procedures and the monitoring of the effectiveness of these procedures as they apply to the individual woman' (Department of Health 1982). They were expected to advise where services were deficient and make recommendations on how they could be improved.

Table 3.1: Policy developments relevant to MSLCs

YEAR	GOVERNMENT POLICY OR INITIATIVE	SUMMARY OF ADVICE
1984	The Maternity Services Advisory Committee report	Recommended the setting up of MSLCs. MSLCs to agree procedures and monitor their effectiveness; and make recommendations on how services can be developed
1992	The Health Select Committee (Winterton) report	Recommended the role of MSLCs should be strengthened through better integration with planning processes.
1993	The Changing Childbirth report	Described MSLCs as a very important way of involving users in planning and reviewing services
1994-1998	NHS Executive Changing Childbirth Implementation Team	Set up by the Department of Health to raise awareness of Changing Childbirth and provide support for its implementation. Acted as a resource for MSLCs
1996	MSLCs: Guidelines for working effectively	Produced by the Changing Childbirth Implementation Team. Provided advice on MSLC structure and procedures

Subsequent government documents to do with maternity services confirmed the importance of MSLCs and provided advice on how they should develop. The suggestions were a combination of vague but ambitious expectations that MSLCs should be more influential in maternity service developments and specific advice in

relation to improving user representation and participation. The government's review of maternity services in 1992 drew attention to the potential contribution MSLCs could make to the promotion of women-centred services. The report of the Health Select Committee concluded that MSLCs were not adequately involving local women and recommended that their role should be strengthened by increasing the lay representation and improving the integration of MSLCs in the planning process (House of Commons Health Committee 1992).

The following year, the Expert Committee set up to make policy recommendations suggested that the committees would better incorporate the user perspective if the chairperson was independent of the main professional groups providing maternity care (Department of Health 1993a). The *Changing Childbirth* report that followed from the review described MSLCs as one of a variety of different ways that users can be involved in planning and reviewing services and suggested that their role should be strengthened (Department of Health 1993a). It stated that user representation should be sought from as wide a base as possible including community health councils, local voluntary organisations, consumer groups and individual mothers. It encouraged MSLCs to look to the guidance contained in *Local Voices* (Department of Health 1991) on how to involve users who would not normally come forward as representatives.

Recent developments

In 1994, the Department of Health set up the NHS Executive Changing Childbirth Implementation Team to raise awareness about *Changing Childbirth* among health professionals and the public and to act as a resource for those involved. Part of their remit was to promote the development of MSLCs and support them in their endeavours to implement *Changing Childbirth*.

In 1996, the NHS Executive Changing Childbirth Implementation Team launched guidelines for the effective working of MSLCs (NHS Executive 1996). These aimed to strengthen user involvement and encouraged MSLCs to develop a more strategic role. The guidelines were developed by a multidisciplinary working party that included obstetric, midwifery and lay representation. They provide a model Terms of Reference and a checklist which can be used by MSLCs to identify areas that need improvement. They provide detailed suggestions about membership and emphasise the importance of building close links with the health authority. They describe several potential areas of work for MSLCs and these are summarised in Box 3.2. MSLCs are expected to be involved in developing and monitoring maternity strategy, in reviewing maternity guidelines and monitoring their implementation, in providing information for users, and in ensuring local users are consulted about maternity services. In addition, the document states that MSLCs have a key role to play in the successful implementation of the *Changing Childbirth* programme and in promoting evidence-based maternity care.

The growth of MSLCs

A survey commissioned by the Department of Health in 1984 found that 63.2% of district health authorities had MSLCs (Garcia 1987). Eight years later, in 1992, a survey by the Royal College of Midwives found that 88% of the responding district health authorities and Health Boards had a MSLC (Royal College of Midwives 1992). A more recent survey in 1996 by the NHS Executive Changing Childbirth Implementation Team identified well over 100 MSLCs. It appears that there is now at least one MSLC in every health district.

Box 3.2: Guidance on the remit of MSLCs in the NHS Executive guidelines

WHAT MSLCS CAN DO
Strategy MSLCs need to be involved in developing strategies for maternity services and need to be aware of the authority's overall plans for health services and the resources available to the health authority. It is up to the MSLC to look at what it would like to achieve and make its case to the health authority. Information for women MSLCs can assist health authorities in producing information for women about the range of services available from the different providers with whom the health authority has contracts; and advise on what information women find useful. Consultation with users In addition to user members on the committee, the MSLC needs to find out the views of current and recent users. Effort will need to be made to seek the views of a wide range of local users including minorities and those on low incomes. Quality standards and contracting The MSLC should be consulted during the development of service specifications for maternity services and involved in yearly reviews. The MSLC should receive details of contracts each year. Audit and monitoring MSLCs can take local priorities from the *Changing Childbirth* initiative and set goals and review progress. They will need detailed information about services, protocols and guidelines. MSLCs will be involved in monitoring users' views, either directly or through involvement with monitoring work done by providers or the health authority. They will be consulted on clinical audit priorities and be provided with the results of clinical audit. They should promote research in important areas. They can monitor services through reviewing feedback from users in the form of complaints and letters. Guidelines MSLCs are not responsible for producing guidelines, but can play a part in reviewing and developing guidelines for local services.

The structure and effectiveness of MSLCs

There is little systematic information on the effectiveness of MSLCs. There have been several surveys of structure which have demonstrated the variation between committees and enable assessment of the extent to which MSLCs have met policy expectations; and a small number of surveys of MSLC members for their views on the effectiveness of their committees. There has been no systematic study of the activity or process of MSLCs.

The structure of MSLCs

There have been four reported questionnaire surveys of MSLC structure and these are described in Table 3.3. Three were nationwide surveys and the fourth was of health authorities in London. The surveys collected information on a variety of aspects of MSLC structure, including accountability arrangements, composition, remit and frequency of committee meetings.

Table 3.3: Surveys of MSLC structure

YEAR	METHODOLOGY	CONDUCTED BY	MAIN AREAS COVERED
1984	Nation-wide postal questionnaire survey of directors of midwifery services in English health districts (93% response rate; n = 180)	National Perinatal Epidemiology Unit (funded by the Department of Health)	The existence and structure of MSLCs (one component of a wider survey of policy and practice in midwifery).
1992	Nation-wide questionnaire postal survey of all UK district health authorities and health boards	Royal College of Midwives	Composition Remit
1994	Postal questionnaire survey of directors of public health in all 16 London health authorities (90% response rate)	The Greater London Association of Community Health Councils (GLACHC)	Composition Frequency of meetings
1996	Nation-wide postal survey of MSLC chairpersons in England* (121 replies; response rate not reported)	Changing Childbirth Implementation Team (CCIT)	Composition: To form database of information on MSLCs

* There was no report available of the findings of the questionnaire survey. Data reported in this thesis was collated from the questionnaires by D Berrow.

The main aims of the first surveys were to find out how many MSLCs had been set up and how many of these included users in their membership. By 1992 there was evidence that most districts had MSLCs and subsequent surveys sought more detail about composition and procedures. The comparison of survey data is hampered to

some extent by low or unreported response rates and variation in the type of respondent. However, the data provide some indication of general trends in the development of MSLCs.

Types of MSLC

MSLCs have different accountability arrangements and vary with regard to the number of maternity units their remit covers. Policy expectations have been that MSLCs should be set up and maintained by health authorities (Department of Health 1993a; NHS Executive 1996). However, in practice many MSLCs were set up in hospital trusts and have a range of input from the health authority. Over time, the health authorities in some areas became more involved and in some cases the MSLC has become formally accountable to them (Cowl 1997). In some districts where there is more than one main hospital maternity unit, the health authority has set up district-wide committees to cover the work of all units. In some such areas, local committees relating to individual hospital units continue to exist alongside the district-wide group and there is therefore more than one MSLC in these health districts. The survey of London MSLCs found more than 26 MSLCs within the 16 London health authorities (Joule 1995).

The 1996 survey provided some information on accountability arrangements. Just over half the respondents (53%) reported that their MSLC was formally accountable to the health authority and 24% considered they were accountable to a hospital trust. Twelve per cent of the respondents considered the MSLCs accountable to both health authority and provider unit. The surveys have shed light on some substantial differences between MSLCs in terms of their age, their relationship with the health authority and the number of maternity units covered in their remit. What impact these features have on the functioning and effectiveness of MSLCs is not known.

Membership

The survey in 1984 found that most MSLCs had a common core of professional members consisting of one or more consultant obstetricians, consultant paediatricians, midwives, general practitioners (GPs) and administrators. Many also included health visitors, social workers and health education officers (Garcia 1987). Only 56% had lay members, and most of these had only one such person.

There has been an increase in the number of user members on MSLCs since this survey. By the time of the Royal College of Midwives' survey in 1992, 92% had user representation and nearly half of the committees had more than one lay member (RCM 1992). There has also been an increase in the range of users represented. Most of the original user representatives were CHC members or district health authority members, but by 1992 over half the MSLCs had a National Childbirth Trust (NCT) representative and some also included members from other consumer organisations. The 1996 survey found that nearly all (96%) of MSLCs had more than one user member. The average number of user members per committee was four. Twenty-six per cent had two users, 28% had three, 10% had four and 31% had five or more.

The NHS Executive guidelines suggested that users should form one third of the membership. The 1996 survey (which took place in the same year the guidelines were launched) showed that 20% met this requirement. A greater proportion of committees that were accountable to health authorities and covered more than one unit met the requirement than other types of committee (26% compared to 15% of those that covered one unit and were accountable to health authorities and 17% of those accountable to hospital trusts.)

MSLC size

There is substantial variation in the size of MSLCs. The survey by the Royal College of Midwives in 1992 found membership ranged from seven to thirty and the 1996 survey established a range from seven to 29. Most MSLCs had under 20 members. There was a large overlap in the ranges of membership for MSLCs with different accountability arrangements (10 to 29 and 7 to 22 for MSLCs accountable to health authorities and hospital trusts respectively), but many of the largest committees were those accountable to health authorities that covered more than one unit, and many of the smallest were accountable to hospital trusts.

Chairperson

Most MSLCs were initially chaired by consultant obstetricians (Garcia 1987), but many changed over to lay chairship in the 1990s. Lay chairship was promoted in policy documents as a way of reducing the domination of meetings by health professionals (House of Commons Health Committee 1992; NHS Executive 1996). The survey of London MSLCs found that half the MSLCs had lay chairpersons (Joule 1995). The 1996 national survey found that well over two thirds were chaired by lay persons and some of the other remaining MSLCs had plans to establish lay chairs. The definition of lay chairperson in the surveys included non-executive directors of health authorities or hospital trusts. There is some evidence that since the 1996 survey many more MSLCs have adopted lay chairship. There is no exact figure available, but the author's contact with MSLCs during the present study showed that committees that were reported in the survey to be chaired by health professionals had since changed to lay chairship.

Frequency of meetings

There is some evidence of an increase in the frequency of MSLC meetings. The 1992 survey found that just over half met three times or more in one year and the 1996 survey found that most MSLCs met four or more times. The guidelines suggest that MSLCs meet not less than four times a year in order to maintain continuity, commitment and momentum (NHS Executive 1996). It seems that many are achieving this or attempting to.

MSLC remit

There is little known about the work done by MSLCs. The 1996 survey asked one question about remit where respondents were required to indicate which of nine potential areas the MSLC was involved with or consulted on. These areas of work are suggested as appropriate areas of work for MSLCs in the NHS Executive guidelines (NHS Executive 1996). No information was collected on what the work in these areas or the MSLC involvement amounted to. The percentage of MSLCs that were reported to have a remit in each area are shown in Table 3.4.

Table 3.4: Responses to the CCIT survey question about MSLC activity

PER CENT OF MSLCS REPORTING THEY DID WORK IN EACH AREA (n=121)*					
information to service users	89	service planning	73	service specifications	56
obtaining users' views	83	service monitoring	71	complaints	41
quality standards	74	clinical protocols/ guidelines	62	clinical audit	37

(* The data was collated from the questionnaires by D Berrow)

Most MSLCs reported they had a remit to do with information for users and obtaining users' views; and approximately three-quarters in each case were reportedly involved with quality standards, service planning and service monitoring; but less than half in each case did work in relation to complaints or clinical audit. There was therefore some indication that MSLCs were not working in all the areas suggested in the guidelines. Some MSLCs reported that they were in the process of reviewing their remit.

The survey findings were examined for any differences in areas of work between MSLCs accountable to health authorities and those accountable to trusts. MSLCs have been encouraged in policy documents to develop greater health authority input in order to promote a more strategic input to the planning and monitoring of maternity strategy (Department of Health 1993a, NHS Executive 1996). The survey found only small differences between the two main types of MSLCs (data not shown in table). The largest difference was with regard to clinical audit where 42% of those accountable to health authorities reported involvement compared to 28% of MSLCs accountable to trusts.

The 1996 survey collected copies of the responding MSLCs' Terms of Reference and these could, in theory, be a useful source of information about MSLC activity. However, many MSLCs had adopted the model Terms of Reference produced by the National Childbirth Trust in 1993 or had documents which had only vague aims and objectives, and were therefore a poor source of information.

There is some anecdotal information available on the activities of MSLCs. The NHS Executive guidelines includes examples of MSLC initiatives. They described a consumer subgroup set up by one MSLC to report the views of women to the MSLC and an information group set up by another bringing together members of the three

MSLCs in the district to review information provision throughout the area. With regard to audit and monitoring, the guidelines described the Effective Care Project which was set up by members of Camden and Islington MSLC to promote research based practice in specific areas of care in local trusts (Duff and Hayward 1998). There is no information on the impact or effectiveness of the projects, with the exception of the Effective Care Project. This was evaluated by the author of this thesis and her supervisor and found that the project promoted reviews of policy and audit, but was limited in the extent to which it changed practice (Humphrey and Berrow 2000, Berrow et al 1997).

Members' views on the effectiveness of their MSLCs

Three surveys of members' views on MSLC effectiveness and / or their experiences of membership have been undertaken to date. These are described in table 3.5. The first survey in 1991 was a small and informal survey of NCT members on health committees by the NCT (Newburn 1992). Thirty-two of the 41 accounts of their experience sent in to the NCT were from MSLC members. While there are limits to the generalisability of the findings, they provide information on the problems perceived by some user members. The second was a survey of MSLC members in North Thames conducted by the NCT as a component of an initiative called C*hoices* which also included a survey of users of maternity services (Gready et al 1995). The third survey was a nationwide needs' assessment conducted by the NCT and University of Hull to identify the training needs of user members (Fletcher et al 1997). This has been included in this section because it provides systematic information on the views of members.

Table 3.5: Surveys of MSLC members on the effectiveness of MSLCs

YEAR	METHODOLOGY	CONDUCTED BY	MAIN AREAS COVERED
1991	An informal survey of 32 NCT members	National Childbirth Trust (NCT)	Experiences of members and views on effectiveness
1996	Questionnaire survey of all members of the 15 MSLCs in North Thames region (69% response rate; 192 replies)	Component of *Choices* project run by the NCT and funded by North Thames office of NHS Executive	The experiences of members of participating in the MSLC; views on effectiveness; knowledge and use of evidence-based materials
1996/ 97	Postal needs' assessment of user members in England (48% response rate; 182 replies)	Component of *Voices* project run by the NCT and School of Health at the University of Hull; funded by Department of Health Changing Childbirth monies	Confidence to participate; effectiveness of the MSLC; and training needs of members

The information available from the surveys is limited in several ways. The surveys were conducted by the NCT which, as a user organisation, has an interest in establishing the problems experienced by users on MSLCs and in promoting user participation. One of the three surveys sought the views of other members of the MSLCs, although health professionals were not asked about their experiences at meetings. The surveys used mostly closed questions and were therefore biased towards the problems that the researchers believed to be important. One of the surveys had a low response rate and another solely focused on user members from the NCT. However, despite problems of generalisability and comprehensiveness, the survey findings provide some insight into the views of those participating in MSLCs.

Effectiveness of MSLCs at influencing maternity services

Two of the surveys sought respondent views on the effectiveness of MSLCs at influencing maternity services. The survey of NCT members found that many reported

their MSLCs had no policy or monitoring function (Newburn 1992). The *Choices* survey found that only 37% of respondents in each case thought their MSLCs made written recommendations to purchasers or providers or had been involved in setting specifications for maternity services (Gready and Newburn 1997). Respondents were asked to rate the effectiveness of their committees on a scale from 1 to 5, where 1 was not at all effective and 5 represented maximum effectiveness. Twenty-seven per cent rated their committees as effective (with a rank of 4 or 5) and 37% rated them as ineffective (giving a rank of 1 or 2). When asked to elaborate, those who did not consider their committees to be effective commented on poor attendance, lack of purpose and difficult team dynamics.

Participation by user members

All three surveys collected some information from users about their level of participation. The *Voices* survey asked for an overall assessment of how effective the respondents felt they were at participating in meetings. Thirty-five percent reported that they had been effective and 24% reported that they had not been effective. The *Choices* survey asked user members how much they participated at meetings. Under half (46%) responded that they usually joined in the discussion throughout the meetings. In rating how well the committee worked as a team, user members were much less positive than professional members (no figures available).

Many lay respondents rated themselves as lacking the confidence to participate fully at meetings. The survey of NCT members found that many felt intimidated (Newburn 1992). The *Choices* and *Voices* surveys found over half the users were confident about asking questions at meetings, but fewer were confident about challenging other

members of the committee. In addition, 48% of those in the *Voices* survey did not feel confident about presenting evidence to the MSLC (Fletcher et al 1997).

The *Choices* survey found that while many user members reported they were confident enough to put items on the agenda only a small number (21%) did actually did so and 13% did not feel confident to do so at all (Gready and Newburn 1997).

Training needs

The *Choices* and *Voices* surveys asked lay respondents to identify their training needs from a selection provided in the questionnaire and this provides some information on what members perceived to be problems. The surveys identified needs for greater knowledge of the NHS and how to properly represent users on the MSLC. In addition, the *Choices* assessment identified a need amongst some users for access to research-based information and skills in understanding it and the *Voices* project identified a need for training in how to bring about change on the committee.

The *Choices* survey also asked respondents about their knowledge and use of evidence-based materials. The NHS Executive guidelines suggested that a potential role for MSLCs was to ensure maternity services were developed in line with research evidence (NHS Executive 1996). The survey findings indicated that many MSLCs were not assessing evidence or discussing its implications to local maternity services. Only half of the respondents thought it important that the MSLC's decisions were based on research evidence. Over three-quarters of the respondents had heard of the Cochrane Database on Pregnancy and Childbirth (CCPC) or the Guide to Effective Care in Pregnancy and Childbirth (Chalmers et al 1989), but only a third reported that they had used either of them. Significantly fewer lay representatives than professional members

had heard of or used CCPC. Respondents were asked to tick which of a list of barriers to using research were relevant to their MSLCs. Over a third of respondents in each case thought there was a lack of time to read research, a lack of skills on the MSLC to interpret research, and a lack of relevant research.

MSLC support and development initiatives

There have been a number of initiatives aiming to provide MSLCs with practical help to improve their functioning and effectiveness. Consumer organisations have been supportive on a national and local level. Both the NCT and Royal College of Midwives have produced guidance for MSLCs (NCT 1993, RCM 1993). The Department of Health has funded several projects wholly or partly to do with MSLCs as part of its drive to implement *Changing Childbirth*, including the *Voices* initiative and the Critical Appraisal Skills Project (CASP). On a more local level, some MSLCs have set up their own support.

The focus of many initiatives has been on empowering user members, although more recently there has been an additional emphasis on promoting team building and skills in critical appraisal. A selection of initiatives are described in further detail below.

<u>The work of consumer organisations</u>

The NCT produced its first model terms of reference in 1993 and these were adopted by many MSLCs (NCT 1993; Lewison 1994). They drew on the recommendations made in government reports (Department of Health 1982, 1984,1985; House of Commons Health Committee 1992) and were produced in response to disappointment that the role of MSLCs had not been clarified in the 1990 reforms (Lewison 1994). In

1992, the NCT and the Greater London Association of Community Health Councils (GLACHC) produced a briefing paper for user members of MSLCs on the history and function of MSLCs (Lewison 1994). In 1993 the NCT published its *Winterton Action Pack* (NCT 1993b) which contained ideas about making MSLCs more effective including the suggestion that NCT branches collaborate with CHCs and other users to strengthen the user view in local MSLCs.

Consumer organisations have also provided training and support for members of MSLCs. In 1995, GLACHC provided a series of training days for lay members of MSLCs in London which included race and disability awareness (Buggins et al 1996) and the NCT's maternity service committee disseminates information about maternity services (Fletcher 1996).

Royal College of Midwives

In 1993 the Royal College of Midwifery conducted a survey of directors of public health to identify the structural features of MSLCs. Subsequently, at approximately the same time as the NCT produced their model terms of reference, the Royal College published its own guidelines for MSLCs (RCM 1993). They are very similar to the NCT terms of reference.

The *Voices* project

The *Voices* project aimed to provide training and support for maternity service user representatives and was a joint endeavour between the Institute of Nursing Studies at the University of Hull and the National Childbirth Trust which (Fletcher 1996). The

initiative built on work undertaken by GLACHC in 1995 which provided support and training for lay members of MSLCs in the London area.

The project aimed to increase the awareness, confidence and effectiveness of user representatives (Buggins et al 1996). From 1996 to 1997, the project team conducted a needs' assessment (described earlier in this chapter) and ran training courses around the country for current and potential maternity services user representatives across the country. Over one hundred people attended these courses and most reported that the training had made a difference to the way they worked on the committees. The project team also produced a resource pack for user representatives that contained information about the NHS and guidance on how to become an effective user representative, and set up training days specifically for lay chairpersons.

The Critical Appraisal Skills Programme

A second project funded by *Changing Childbirth* monies was the Critical Appraisal Skills Programme (CASP) run by the Oxford and Anglia Health Authority (Crowe 1997). Originally this programme had been directed to health authorities, but was adapted for use by MSLCs. The aim of the project was to give MSLCs the skills to promote evidence-based decision-making in the care of women during pregnancy and childbirth. At workshops members learnt about the different sources and types of evidence, conducted a critical appraisal of a systematic review, and examined how research evidence could be integrated into the work of their MSLCs. The project identified the difficulties MSLC members experienced gaining access to sources of evidence. Over 200 people from 20 MSLCs attended these workshops and many felt more confident about contributing to MSLC discussions and decisions as a result (Crowe 1997).

The *Changing Childbirth* Implementation Team

In 1996, the NHS *Changing Childbirth* Implementation Team launched new guidelines for MSLCs at conferences in London and Manchester (Cowl 1997; NHS Executive 1996). MSLCs made presentations on their work and there were workshops to help members with problems they experienced on their committees (personal attendance and Cowl 1997).

The Implementation Team also supported MSLCs in other ways. Its survey of MSLCs in 1996 (described earlier) enabled it to set up a database of MSLCs in England and Wales which provides a source of information on MSLCs and contacts for research and training initiatives (NCT 1995). In addition, it produced a quarterly newsletter entitled *Changing Childbirth Updates* to report on progress around the country in meeting the requirements of *Changing Childbirth* and to disseminate information about MSLCs (Cowl 1996). The Team was also responsible for monitoring some of the work funded by *Changing Childbirth* monies, including the CASP project described above.

The Team was disbanded in 1998 and responsibility for the database and *Changing Childbirth Updates* magazine passed to the National Perinatal Epidemiology Unit at the Radcliffe Infirmary in Oxford.

Local support

Some MSLCs have set up their own sources of support. For example, in 1997 the MSLC in North West Lancashire organised a half day programme of speakers and group work for MSLCs in the North West (Key 1997). This provided the opportunity for

members to raise concerns about MSLC effectiveness and discuss potential solutions. In London, GLACHC runs quarterly meetings and has provided training for lay representatives of MSLCs in London (Fletcher 1996).

Conclusion

MSLCs are now present in all, or nearly all, health districts in England and Wales. They vary in size, membership and accountability arrangements. Research into the effectiveness of MSLCs has been limited to surveys of structure and the views of members. Surveys of structure have demonstrated an increase in user membership - which was slow to be implemented in some areas - and an increase in health authority input. However, there continues to be minimum user representation in some MSLCs. Surveys also found that many MSLCs were not involved in planning and monitoring activities such as complaints and clinical audit. Surveys of members for their views on the functioning and effectiveness of their committees found widespread dissatisfaction and user members reported many barriers to their involvement. The extent of the problems perceived by user members is reflected in the plethora of initiatives that have been set up to support them.

Chapter four:

The user voice in the NHS

This chapter investigates the development of user involvement in the health service in the United Kingdom. Firstly, the chapter looks at the meaning of the term user involvement and the range of activity it encompasses. The next section looks at the changing attitudes to medicine and the wider changes in society which have led people to become less passive in relation to their health care and the health service in the past half century. The extent to which these changes have challenged the standing of medicine is then discussed. The subsequent section looks at how user involvement has developed within the health service and examines the motivations behind these developments. The barriers to effectiveness associated with the mechanisms presently available for user involvement are then reviewed. The final section assesses the extent of user involvement in the health service and shows how progress has been shaped by the structure and policies of the health service, the high level of professional dominance that exists, and characteristics of users themselves.

Terminology and classifications of user involvement

In this thesis 'user involvement' is defined very broadly to include any mechanism whereby members of the public can express their views on the health service or the healthcare they receive. It covers any degree of involvement, from providing feedback on specific services to participating in the decision making process with regard to how services are developed. It encompasses people's involvement as individual service users with concerns about the accessibility, nature and quality of particular health interventions, and the extent to which health professionals involve them in treatment decisions; and their collective involvement as citizens with an interest in local service

provision and the principles and priorities of the national health service on a wider scale. Throughout the thesis, the term 'user' encompasses actual and potential users of care.

There is a plethora of terms in use that relate to user involvement. People are variously called patients, customers, consumers, citizens and the processes are involvement, participation, empowerment and consultation. These terms are often used interchangeably, yet can imply different ideas about involving people. In addition, the same terms have different meanings to different people. Behind an apparent consensus in the use of terms such as choice, user empowerment and consultation there are diverse ideas about what user involvement is and should aspire to be. One person's commitment to patient involvement may involve a desire to involve them in treatment decisions yet a second person's interest may be in administering questionnaires to patients to obtain their feedback on the care they received. This confusion makes it difficult to assess the motivations behind user involvement activity.

There are several classifications of user involvement in the literature which help to demonstrate the range of activity that user involvement can encompass. They are used later in this and in chapter twelve to evaluate user involvement in the health service and in MSLCs respectively. In the UK, Klein has written of a continuum from professional dominance to consumer dominance, moving from information provision and consultation, through negotiation and participation, to the power of veto (Klein 1975). In the United States, Arnstein conceived a typology of eight levels of participation arranged in a ladder pattern with each rung corresponding to the extent of citizens' power in determining the end product. Lower rungs, such as manipulation, reflect non-participation; middle rungs of informing, consultation and placation reflect degrees of tokenism; and the upper rungs of partnership, delegated power and citizen

control signify degrees of citizen power (Arnstein 1969). Maxwell and Weaver have described five activities that fall within the definition of public participation, reflecting increasing degrees of user involvement: consumer protection, public consultation, openness of managerial decision-making, full management participation by public representatives, and heightened individual and community responsibility and power (Maxwell and Weaver 1984).

These classifications have a similar conceptual base, but Arnstein (1969) uses less neutral terms to describe activity at the lower end of the ladder or continuum, emphasising the cynical nature of some user involvement activity where the hidden agenda may be to shape the views of users in line with a policy or practice rather than to let users exert an actual influence. Maxwell and Weaver's classification (1984) is helpful because it draws out the difference between openness in decision-making and real user participation in decisions - a distinction that will be pertinent to lay representation on committees and groups and one that might only become clear from close observation.

Papadakis and Taylor-Gooby (1987) have conceived of user involvement in a somewhat different way. They have distinguished three forms of potential participation: choice, voice and control. In relation to health, choice might include opportunities to choose between services or healthcare interventions and voice might be about being consulted on the development of local services. Control cuts across all activity and is the extent to which the user has power in any of these areas.

Changing attitudes

When the health service was developed in 1948 people were seen as passive recipients of public services and this paternalism was reinforced by health policy and indeed in social policy in general. However, since that time people have become more questioning and less trusting in their dealings with health professionals. People have become more active in relation to their health on both an individual and collective level. Paternalist behaviour is no longer automatically seen as acceptable. These changes have informed and been reflected in recent social policies, albeit modified by political ideology and ambitions.

Why have people become more active in relation to their health? It can be argued that the limitations of medicine have become more obvious and the assumptions of effectiveness and scientific legitimacy on which medicine is built have been questioned. Secondly, there is evidence of fundamental changes in society in the way people relate to authority and value professional expertise. And thirdly, while in the past people had to rely on health professionals for information about health care and the health service, they now have greater access to information about these things through the mass media and as a result of policy initiatives in the health service. These three factors are now examined in more depth.

The limitations of medicine and doubts about effectiveness

The NHS was set up at a time when there was a high degree of faith in the ability of medicine to find cures for modern diseases and deliver improved health for the population. The rights of the medical profession to collective autonomy and individual clinical freedom were taken for granted and protected in the new health service. Klein

(1983) argues that the special role and concessions accorded to the medical profession reflected three key beliefs prevalent at the time: that medical science had triumphed over disease in the past and would continue to do so; that medical support and co-operation was crucial to the success of the proposed health service; and that professional autonomy was a necessary and appropriate form of management for those essential, and essentially benevolent, occupational groups such as medicine whose esoteric knowledge bases required them to be self-governing and independent from interference from the state.

In the 1970s optimism and faith in the benefits of modern medicine and the altruistic nature of the medical profession gave way to disillusion and doubt as medical costs soared with little apparent benefit. A number of influential critiques of medicine provided reappraisals of medicine and its contribution to promoting health. Medicine had failed to find a cure for major causes of death such as coronary heart disease and cancer. Chronic illness and disability had replaced infectious diseases as the major health problems and medicine seemed to have less to offer these conditions (Hogg 1999). In Britain, inequalities in health status between classes persisted in spite of thirty years of a free health service (*The Black Report*, DHSS 1980). There was growing evidence that major causes of health inequalities lay beyond the NHS and were rooted in the material conditions of life. Therefore the assumption that the medical profession could address these began to appear misguided and naive.

There were growing doubts about the key role played by doctors in the maintenance and restoration of health (Powles 1973; McKeown 1979). McKeown conducted an analysis of English and Welsh death records kept since 1847 and concluded that the contribution of medical intervention in contributing to the decline in mortality had been considerably over-emphasised (McKeown 1979). He found that most important

diseases had begun to decline in significance well before medical interventions had been introduced. He attributed the reduction in mortality to improvements in nutrition and environmental measures such as better sanitation and improved water supply. McKeown's work has been criticised for failing to give credit to medicine for its impact on reducing morbidity and improving quality of life, but his work stands as an assessment of past limitations of medicine not previously recognised.

Cochrane also questioned the effectiveness of medical interventions. He showed that many medical interventions were of dubious scientific status and that fashion, whim and personal preference dictated a doctor's choice of procedure more than information on effectiveness - which did not exist in many areas (Cochrane 1971).

A more radical critique came in the form of the medicalisation thesis. This challenged - and continues to challenge - the scientific basis of medicine by showing how experiences and behaviours which can be considered normal and not needing medical intervention have been reclassified as medical problems and become subject to medical control. Critics question the scientific basis for these developments and consider the harm that it can do to people. The women's movement focused on the way medicine had pathologised pregnancy and childbirth, with the consequences for childbearing women of a reduction in choice and loss of autonomy. In addition, medicine kept them in the dark about the adverse effects of obstetric practices (Oakley 1980). More recently there have been criticisms of the way the menopause has been pathologised and women encouraged to consider their symptoms abnormal and requiring medical intervention (Greer 1991).

Ivan Illich provided one of the most extreme critiques of the medicalisation process of modern Western medicine. He considered all medical intervention to be of little value

and positively harmful through processes of iatrogenesis (Illich 1976). He regarded clinical iatrogenesis as arising because of the ineffectiveness of most interventions and the prevalence of serious side effects; social iatrogenesis as the passivity and dependence on medicine which has been generated by increasing medicalisation of aspects of life such as old age; and structural iatrogenesis as the extreme result of the medicalisation of life which destroys autonomy leaving people without the ability to cope with pain and death in a meaningful way. He considered the way to resolve the problems was to destroy medicine in its present form. While he can be criticised for exaggeration, his work has illuminated the harm that can arise through medicine and the ways in which medicine can reduce the power of people to take care of themselves.

The sociologist Freidson considered that the medical profession's power to control what constitutes health and illness had been used to extend the medical monopoly over areas of life and behaviour which were not traditionally the concern of the medical profession. This medical dominance arose from doctors having gained monopoly legal and political rights of control over diagnosis and treatment from the state (Freidson 1970). Friedson saw autonomy as the key to professional power. This gives the professional group the right to determine who can legitimately do its work and how the work should be done. A knowledge monopoly helps the profession to gain and maintain this autonomy. The power to define what requires medical attention and what this should be rests solely with doctors. This analysis of medical power by Friedson and Illich took place within a wider sociological critique of professions and professionalism. Medicine was one example, but the arguments were seen as relevant to all professional groups.

Some critics argued that medical dominance is promoted and maintained by other interests in society in addition to professional self-interest. Illich attributed the medicalisation of life to the increasing professionalisation and bureaucratisation of society associated with the advent of industrialisation, although the medical profession contributed by mystifying the public about the real causes of ill health (Illich 1976). With regard to mental health, Szasz considered the way the state uses psychiatry to control unsocial behaviour (Szasz 1971). Others have looked at the multiple interests that can be served by medicalising a problem or type of behaviour (Conrad 1975). A medical diagnosis can promote commercial interests such as those of drug companies and also benefit families and patients themselves where it protects them from feelings of responsibility and guilt. These analyses provide insights into the sources of professional power and the way in which self-interest may be rationalised in the public good with regard to the practice of medicine.

Feminist and Marxist critiques have drawn attention to how medicine may institutionalise prejudice or class distinctions that exist in wider society. Feminists have looked at how the practices and institutions of modern medicine control and disempower women both as consumers and producers of health care, and are unresponsive to their needs. They have been critical of how medicine has ignored the social causes of ill health in women which have their roots in the inequalities they live with (Oakley 1983). Feminist analysis includes the study of how a predominantly male medical profession has been instrumental in defining women's experiences as abnormal events that require medical input.

Those looking from a Marxist perspective start from the premise that modern medicine is part of the capitalist mode of production and functions to preserve the existing social relations and continued dominance of the bourgeoisie. Medicine's contribution is

maintaining the health of the labour force. For example, from a Marxist perspective discrimination against older people in the allocation of health care treatment may be attributed to the lack of value society attributes to people who are not working and do not contribute to the economy. Marxist analysts attribute medical power to class position and argue that the behaviour of doctors - and that of all professional groups - is to perpetuate the class system. Professions help to depoliticise social problems, treating them as personal problems susceptible to individual solution by experts (Wilding 1982). This avoids having to acknowledge the social and environmental determinants of ill health and therefore the costs borne by the lower classes in perpetuating the existing economic system (Navarro 1980, 1986).

More recently, racist critiques have looked at how a predominantly white middle class medical profession reinforces wider prejudices in society. The media has highlighted the extent of racism within the health service. A report commissioned by the Department of Health has found that health professionals from ethnic minorities are abused by patients and other health professionals and that they are discriminated against in terms of career development (Coker 2001). There is also concern that racial groups are discriminated against in medical treatment. This is supported to some extent by the continuing health inequalities that exist between racial groups. The idea of racist institutions is presently on the wider political agenda, particularly in relation to policing.

In summary, medicine has been assailed on many fronts. The effectiveness of medical interventions has been questioned and there has been consideration of the harm that medicine can do. There is greater awareness of the nature of professional authority and the way this has been exercised to gain control over areas of health. Feminist, racist and Marxist critiques have encouraged people to reassess the way

structures and processes of medicine may promote or maintain inequalities. The picture that has developed is that medicine cannot any longer automatically be seen as a wholly scientific, objective and value-free system. These critiques have shaped the intellectual climate and influenced debates for change.

Disillusionment and loss of deference

Concerns about the limitations of medical interventions can be understood within wider social changes in the way people behave and relate to those in power. There has been a questioning of the assumption that 'experts know best' and can be trusted to work in the public's best interest. This has not just been in health but has pervaded other areas such as education, housing, social care, mental health, the law and the police. Commentators write of a change in the relationship between lay people and professional 'experts' (Giddens 1990, 1993; Biggs 1997). Biggs argues that the growth in user involvement can be understood in context of a profound shift in social relations associated with postmodernity (Biggs 1997).

> 'Whereas the guiding principles of modernity can be thought of as a belief in progress, technical expertise, order and values that are universal, postmodernity is marked by a suspicion of big science, that progress from one perspective may mean calamity from another, an awareness of diversity that sometimes verges on fragmentation and a sense of riskiness and uncertainty pervading social life.' (Biggs 1997 p195)

Biggs argues that the shift reflects the wider society moving to post modernity where traditional boundaries between groups - such as those between doctors and patients - are being redrawn (Biggs 1997). The value of science is questioned and by association the idea that "doctor knows best" is challenged. The decline in professional authority has in part been attributed to the emergence of a more educated and more egalitarian society (Haug 1988). More people have been educated to a higher standard and as a consequence are not so in awe of authority figures.

The changes have led to an erosion of deference. People have become less trusting of all professional groupings, bureaucracies and power structures. The effectiveness and altruistic nature of institutions such as parliament, the police and the law have been questioned. An absolute belief in the altruistic nature of professionals and the benevolence of public institutions is no longer a strong feature of society and has led people to fight for greater protection of human rights in many different spheres, including the police and prison services, as well as in international politics where humanitarian concerns appear to come second to promotion of the global free market.

In health, people are less trusting in the altruism and infallibility of doctors (Hogg 1999). The editor of the British Medical Journal has written that "democracy in all its messy forms is taking over everywhere. Professions are suspect, paternalism is in decline and there is a rightful increase in demands for accountability" (Smith 1991). People are sceptical about medicine but they are just as likely to be sceptical of managers in the health service or suspicious about the motives of politicians. For example, McIver and Martin observe that the widespread scepticism and cynicism about Patient's Charter and league tables (see section on health policy) seems to be linked with current disaffection with politics and politicians (McIver and Martin 1996).

There is evidence of rising dissatisfaction and disillusionment with the health service. In 1948 an austerity NHS was born in an austerity Britain and people were grateful for what they received (Ranade 1997). Rationing and queuing were symbols of fairness in the distribution of scarce resources. By the 1980s this society had been replaced by an affluent consumer culture. For most people, expectations were no longer blunted by experience of poverty. The politics of the New Right in the 1980s and early 1990s provided ideological legitimacy for consumer assertiveness through its emphasis on consumer power, competition and greater access to information on medical outcomes

(Green et al 1990; Gladstone 1992). Queues in the form of waiting lists are now more likely to be seen as a sign of failure to meet the needs of users rather than a fair way of allocating care. Society has been exposed to a range of new experiences and information through travel and through television and can compare the NHS with health services in other countries. Perhaps the sense of pride in British institutions associated with patriotism is not so strong, on an individual or collective basis.

Access to information

A major development in society which has contributed to the reduction in deference to authority and reduced the public's confidence in professionals is the information revolution. Growth of the mass media has meant that the public has greater access to information about the nature and quality of public services. They are aware of the variation in the quality of services around the country. Television ownership is universal and recently the internet has increased access to information. The media has turned its spotlight on traditional institutions from the monarchy to the NHS. What used to be elite, insider knowledge has been turned into public information. The media no longer seems to self-censure as a form of deference to traditional institutions.

The media has provided a fast network for the distribution of information, publicising cases of poor quality and professional mistakes across all public services including 'failing' schools, failures of social work and community care. The infallibility of medicine has been demonstrated by the media highlighting one mistake after another and laying bare the lack of safeguards in place to protect patients.

There is greater access to information about services and organisations such as schools, hospitals and government policies. The capacity for self-help and sharing

experiences and knowledge with others in a similar situation is no longer restricted by geographical boundaries: information is being shared by people all around the world via the internet. With regard to health, websites catering for specific conditions provide support and information. There has also been a growing industry in self-help books providing advice in a range of areas from buying a house, conducting a divorce, to living with a chronic disease such as arthritis. The Consumer Association publishes a *Which? Guide to Health* that looks at effectiveness issues and how to get the best out of health services.

The increase in access to information is in part attributable to governmental policies of consumerism and managerialism. The rise of managerialism in the 1980s prompted the collection of systematic information on the nature and quality of public services for purposes of measuring and monitoring and the public has had access to this information. This was the case with initiatives such as the introduction of performance indicators and the *Patient's Charter* where health authorities collected data to monitor how well providers met targets. Before this there was little information available on what happened in the public services.

The purchaser-provider split had the effect of raising the visibility of decisions to do with resource allocation. Decisions that used to be covert became more open to scrutiny. The public has become aware that health care is given or withheld by criteria other than clinical need. They are no longer as confident that the allocation is fair or will work in their interests. Well publicised cases, such as that of Child B, where the decision was made not to treat because of a low probability of success, have fuelled the public's fear that money may sometimes be the overriding consideration in treatment decisions (Burgoyne 1997). Media interest ensures that every example of rationing is seized upon and dramatised. In addition, the public has become

concerned that lifestyle factors such as smoking may influence a clinician's decision about how to treat a patient.

In what ways have these developments led to people becoming more active in relation to their health?

The growing disillusionment with medicine, combined with wider changes in society in the way people relate to those in authority and greater public access to information through the mass media has had ramifications for the relationship between individual users and health professionals as patients have become more active in relation to their care. On a collective level the developments have contributed to the growth of the consumer movement in health and in the growth of the advocacy movement. These movements can be seen as attempts to redress the balance of power between users and health professionals.

The more active patient

In general, people are less accepting of the paternalistic nature of the health service and the medical profession and are more active in seeking information about health and health care. Within the clinical encounter they are more assertive, seek to be involved in decisions about their treatment and are more likely to challenge clinical decisions. In addition, patients are more likely to make a statement about their dissatisfaction with medical care by complaining. Between 1983 and 1991 complaints about primary care rose by other one third and those about hospital services more than doubled (Department of Health 1994b). During the same time period, the General Medical Council reported a large increase in the number of complaints it received about the performance of doctors (GMC 1994). It seems unlikely that a catastrophic drop in standards of care was the cause of this substantial rise in complaints and it cannot be explained solely in terms of improved complaints procedures, as significant

attempts to improve these had not been made at that point. It can be argued that the rise in complaints reflected a combination of rising expectations and a lowering of deference to health professionals. It seems likely that by the 1990s the NHS was exhausting the capital of deference and gratitude which had sustained it over the decades.

Dissatisfaction with the limitations and reductionist nature of medicine has led people to seek help elsewhere, from practitioners who take a more holistic approach. Use of complementary or alternative therapies such as homeopathy, osteopathy, herbalism and acupuncture has grown, particularly for long-term, intractable problems (Stone 1995) which are not well served by traditional medicine. The present debates about whether or not such alternatives should be provided by the health service are due in part to the way users have turned to them and have found them helpful. Within the field of maternity services, it could be said that women who choose antenatal classes run by the National Childbirth Trust over classes provided by NHS health care professionals are displaying a form of 'exit' from conventional medicine.

For its part, the medical profession has become more aware that attention must be paid to user involvement, although this is certainly not a central feature of medical practice. There has been growing awareness that patients cannot be treated as "passive fodder for medical practice" (Morrison and Smith 1994 p1099). Obtaining informed consent is now a requirement of medical care (even if expectations are not always met in practice). In part, professional care to explain treatment and its possible risks can be attributed to the desire to share or offload responsibility for decision making or the outcome of that decision in order to avoid litigation if treatment is not successful and the risks have not been explained. Certainly there has been a big increase in litigation cases (Medical Protection Society 2001). However, there is

evidence of professional interest in user involvement that goes beyond meeting legal requirements. For example, guidelines of the Royal College of Surgeons indicate that doctors should go beyond what would be legally required in explaining treatments and risks of procedures. In addition, some doctors have recognised the benefits of improved outcomes of treatment that can arise from involving patients in decisions about treatment, particularly in the management of chronic illness where the social and quality of life implications of various interventions can only be properly assessed by the patient. There have been some innovative projects giving patients a choice of treatments, such as an initiative at the Central Middlesex Hospital where patients used an interactive video programme to help them choose between options for prostate treatment (MacLachlan 1992).

The consumer movement

Consumer organisations have been set up outside the health service to represent the user perspective and provide support and information. Some organisations have a generic focus. For example, the Patients' Association, founded in 1963, challenges medical practice by helping people to complain about poor treatment (Pfeffer & Coote 1991) and the College of Health, set up in 1983, provides the public with information about health services. Other groups represent the interests of particular health service users, or campaign for better care for people with specific conditions such as AIDS. In maternity services there are many groups which support women through pregnancy and childbirth. There are hundreds of consumer and pressure groups. One primary care group alone identified at least 300 different service user and carer groups in its locality (Sang 1999).

Consumer organisations raise awareness of problems, encourage research and campaign for change, as well as providing support and information to individuals. A number of them aim to influence policy, such as the British Kidney Patient Association which lobbies for funding for more dialysis facilities. However, regardless of whether or not they explicitly aim to influence policy, all groups give visibility to their points of view and demands (Klein 1995).

Consumer groups have undoubtedly influenced the nature of health care in some areas (Sang 1999). For example, Action for Sick Children campaigned successfully for parents to stay with their children in hospital. The campaigning of consumer groups in maternity services contributed to the *Changing Childbirth* policy which advocated greater choice in maternity care (Department of Health 1993a). Patient groups have promoted change, for example, people with HIV have refused to be randomised in trials of new drug therapies thereby putting pressure on researchers to find ways of incorporating patient preference into the designs of their studies.

The advocacy movement

The advocacy movement challenges oppression and discrimination by empowering people in their dealings with professionals, by helping them to take greater charge of their lives and dealings with agencies, and by helping them gain confidence, self-esteem, assertiveness, expectations, knowledge and skills. Underlying humanitarian principles stress the importance of people speaking for themselves and making the most of their capabilities. They embrace notions of empowerment, civil rights and equality of opportunity (Beresford and Croft 1993). Since the mid twentieth century humanitarian concerns have been a force behind citizen-led challenges to the medical model and its dehumanising impact. This paralleled what was happening in the

women's movement, the civil rights movement and the gay rights movements in the United States and the self-help movement which emphasised the importance of speaking for oneself and valuing people's own experience over professional knowledge (Hogg 1999).

The growth of advocacy has been a significant attempt by those outside the health service to empower themselves in their dealings with professionals and has been particularly prevalent in the fields of mental health, physical and learning disabilities where people are at a disadvantage because of stigmatization and communication difficulties (Croft and Beresford 1990). The 1980s saw the emergence of strong self-advocacy groups. People First, a self-advocacy organisation of people who have learning difficulties is in touch with more than 100 self-advocacy groups, local, national and international organisations (Croft and Beresford Croft 1990). In mental health, user led organisations such as Survivors Speak Out and the UK Advocacy Network have been involved in the debates and deliberations about mental health policy and practice (Sang 1999).

To what extent have these changes challenged the standing of the medical profession?

The hypothesis of deprofessionalisation suggests that the changes in patient attitudes is symptomatic of a general decline in the cultural authority and legitimacy of the medical profession (Haug 1973, 1988; Starr 1982). Haug posits that medical dominance has been challenged in three important areas: the monopolisation of esoteric knowledge, autonomy in work performance, and authority over clients (Haug 1988). Access to medical knowledge has increased and rising education levels permit more people to understand it. Haug suggests that the challenge may be more obvious on an individual level in that a person who has experience of a condition over a period

of time may well know more about it than the typical house doctor. This section has already described how there seems to be an erosion of authority over patients. Many patients in the Westernised world and perhaps elsewhere are unwilling to give unquestioning obedience to a doctor's authority. With regard to autonomy, doctors have been criticised for the lack of independent regulation of their behaviour and the present Labour government is encouraging the GMC to make improvements. Moreover, the behaviour of doctors has been increasingly subject to organisational and financial considerations. Primary Care Trusts have to manage budgets. There are rules and ethics committees to govern the use of patients in research.

However, these developments do not necessarily translate directly into more control for users. People are more uncertain about the benefits of medicine, seek greater involvement in their treatment decisions and are more likely to question medical advice, but this is not to say that they have moved from a position of unqualified faith in the medical profession to one of total scepticism. People have always made use of other sources of advice and help apart from doctors (Blaxter 1983; Calnan 1988, 1995). And most people still rely on modern medicine when they are seriously ill, particularly elderly people, who have grown up with a dependence on doctors and may be less inclined and less able than younger people to be active in their own health care (Shackley and Ryan 1994). In addition, at times when they feel vulnerable through illness, people may still prefer doctors to take on the responsibility for medical decision making. A possible explanation for this is that passing on responsibility to the doctor helps to offset the potential for regret in the event that they themselves choose a course of action which does not lead to the required outcome (Shackley and Ryan 1994). In this way, avoidance of regret may be a strong imperative for people to make use of doctors and available technologies, whatever their doubts about effectiveness.

An individual's power to choice what type of health care they receive may be limited by financial costs associated with exercising the exit option. If they reject what is offered by a professional in the health service they may not be able to afford to choice private or complementary care. Their capacity to make an informed choice may also be reduced by the paucity of information about the effectiveness of various interventions. These factors mean that many people continue to be heavily reliant on doctors within the health service. They continue to be subordinates in their relationships with doctors because doctors act as the gateway to treatment.

User involvement in the NHS

This section looks at the way in which user involvement has developed within the health service and the reasons behind this. User involvement in the health service, and indeed all other public services, was a non-issue for many years. The development of the new welfare institutions in the 1940s was based on the assumption that state and professional leadership could provide effective public services, whether this was in education, housing, health or social security. The role of the user was largely limited to that of passive recipient. This has changed significantly. In the past twenty years, there has been an increasing concern with patient and public involvement in policy documents and a variety of mechanisms for user involvement have been developed.

However, promoting user involvement has never been a fundamental preoccupation or motivation behind policy initiatives. Governments have had overriding concerns about the costs of public services. More or less since the beginning of the NHS the main political problem to be solved through health policy has been how to control escalating costs. This has been a significant preoccupation of social policy in general.

For example, the costs of education rose as the minimum age for leaving compulsory education was raised and the costs of social security rose as new social rights were conferred and as unemployment rose. When the health service was formed in 1948 it was expected that once the existing backlog of health problems had been addressed the demand for health care would reduce and then be maintained at a lower level. However, medical advances, a rise in chronic conditions, the aging population, and rising public expectations have led to ever increasing costs. The increasing economic problems in the 1970s meant that the costs to the nation became a pressing political issue. Much of the health policy since has focused on controlling the behaviour of doctors in one way or another (Klein 1995). When the national health service began in 1948 politicians could only secure the support of the medical profession by guaranteeing their autonomy within the health service. The outcome of this was that doctors became the major force in shaping the demand for health care, but were not accountable for the financial consequences of their actions. Promotion of user involvement can to some extent be interpreted as an attempt to address professional autonomy.

When the NHS began the public was notionally represented by lay members of management committees, namely hospital management committees, regional hospital boards, and local authority health committees for community services. In the latter case lay members were elected councillors or co-opted members (Levitt 1980). Local authority control of health services was considered but rejected because of the opposition of the medical profession. No expectation of greater public or patient involvement was built into the system, with the exception that patients could complain if they were not satisfied. However, the procedures for making a complaint were complicated and were controlled by health professionals. The health service was slow to improve complaints procedures and introduce an independent element.

Structural change and managerialism

The first significant change to the health service and user involvement arose as a result of the reorganisation of the NHS in 1974. These reforms aimed to control costs of health services by integrating fragmented services and strengthening lines of accountability and managerial efficiency. The reforms led to the formation of several tiers of health authorities. The reforms aimed to divorce professional and user representation from the business of management (Levitt et al 1995; Klein 1995). There were two implications for user involvement: lay representation was withdrawn from most health committees and assigned to new bodies called Community Health Councils[1] and local authorities were to be involved in new health authorities - at least one third of all members were to be drawn from local government (DHSS 1975). The previous set up where public representation was through lay members of committees had not been considered successful because such members tended to identify more with the needs of the organisation than with those of lay people. However, a desire to improve user involvement should not be seen as a significant aim of the policy. The overriding aim of the government was to control costs, and more efficient management was the chosen tool. The second implication for user involvement was the involvement of local authorities. However, the voice of local authorities was only strengthened in the new health authorities in 1975 in response to high profile criticism that the new arrangements arising from the 1974 reforms were undemocratic. In addition, a lack of Conservative governmental commitment to local authority involvement was evident when it reduced local authority membership of health authorities in its 1982 reforms.

[1] Membership was to be drawn from local authorities, voluntary organisations and Regional Health Authorities (now replaced by regional offices of the NHS Executive). CHCs had a right to demand information and a right to be consulted over decisions to close down hospitals and other changes.

The involvement of local authorities begs the question of whether or not local authority involvement should be considered an effective or democratic form of user involvement. Local authorities have their own interests which do not automatically coincide with those of local people. In addition, as Klein points out, it may not be acceptable that those anointed with the "holy oil of election for one purpose automatically become sanctioned as an all-purpose democratic representative" (Klein 1995 p124).

Consumerism in the NHS

The 1979 election victory of the Conservative party has been described as the end of consensus between parties with regard to their social policy (Klein 1995). Critics from both sides of the political spectrum agreed that the old public service bureaucracies were bleak, unresponsive and inefficient but their responses to this were different. New Conservative policies signalled the end of the social administrative model of provision in public services. The differences between the Right and Left became greater as the Right focused on containing costs and individualism through efficiency drives such as general management and later the application of market and consumerist principles, and the Left focused on collectivism during its time in opposition.

The emphasis on consumerism in public services by the Conservative government in the 1980s was portrayed as a natural extension of consumerism from the commercial world. Consumerism in the commercial world stretched back to the 1960s when activists such as Ralph Nader led a consumer movement to campaign for more consumer rights. The rhetoric of the New Right enshrined in market reforms was that the bureaucratic inertia of the NHS combined with a high degree of professional

dominance had produced an inefficient service unresponsive to the needs of the consumer and the answer was a devolution of money and power to the consumer.

Market reforms

Between 1979 and 1995 the Conservative government looked for devices which would mimic markets and where competition could be used to control costs. The spheres of education and housing were the first to be opened up to market principles and consumerism. The Education Act of 1980 gave parents more choice over schools and later changes led to parents being represented on school governing bodies. The Housing Act of 1980 provided tenants with a statutory right to buy their council homes. In social services local authorities were no longer to assess need and provide care but were to purchase the care the person needed (DHSS 1989b).

In the health service, aspects of consumerism were introduced culminating in the market reforms in the White Paper of 1989. The White Paper *Working for Patients* proposed fundamental changes in the dynamics of the system (DHSS 1989a). A market place was to be set up by a separation of purchasers and providers of services to increase the efficiency and quality of services. District Health Authorities were to be the purchasers of hospital services. The policy also introduced the notion of GP purchasing through the fundholding scheme. GPs would be allocated a budget from which they would purchase a limited range of services for their patients (DHSS 1989a).

The significance of the policy for user involvement

Despite the rhetoric, the adoption of consumerist principles into the health service can be explained as a mechanism to control costs rather than a drive to involve or protect consumers. The 1989 Reforms were brought about by a crisis of finance in the NHS. The measures aimed to increase efficiency without the allocation of any more public money. The focus on listening to the public and promotion of choice can be seen as something of secondary interest or a public relations exercise. The introduction of general management and other efficiency drives in the early 1980s had generated negative publicity and an emphasis on listening to the public and providing choice instead of efficiency might be more acceptable to the public.

The growth of the culture of consumerism in the health service did require managers and health professionals to consider the points of view of patients in service planning and organisation. For example, the system of block appointments for clinics where all patients arrived at the start of the clinic was replaced by designated appointment times. Patient satisfaction took off as an important concept and the use of patient satisfaction surveys by service providers burgeoned throughout the late 1980s and early 1990s as providers set out to show that their services were superior to those of competitors. However, the focus was mainly on hotel aspects of services. In general, doctors remained impervious to the idea that patients should be more involved in decisions relating to their actual care. The *Patient's Charter* expected doctors to explain treatment to patients but little else. The term user involvement almost became synonymous with measuring satisfaction with services, a very limited definition.

There were pockets of initiatives that attempted to promote patient-centred services. For example, the government funded the implementation of quality improvement

techniques such as Total Quality Management, an approach adopted from the commercial world which looks at the organisation as a system and reviews and redesigns processes around the consumer. However, in practice it proved hard or impossible to change entrenched ways of working and the patient-perspective was sidelined.

Government policy emphasised the role of the user as a consumer and described the market reforms as a way of promoting consumer sovereignty. However, despite the focus on choice and rights, individual users were not consumers in the conventional sense as they were not given the same freedom of choice. The choices that did exist were not necessarily meaningful or promoted in practice. For example, in 1987 it was made easier for people to change their GPs and in theory this promoted choice, but in practice little choice was available, especially in rural areas. Surgeries are becoming larger which restricts choice even further. Even if a potential choice exists, there is little information to help people make an informed decision. In addition, some GPs have made arrangements with neighbouring GPs to accept patients only from a certain geographical area. With regard to secondary care, the new contract culture also had the effect of reducing the choices available as people could only normally be referred to hospitals that had a contract with the health authority.

In reality the new approach was 'management-led' consumerism. The real consumer was the health authority or the fundholding practice rather than the patient. Health authorities were to be 'champions of the people' (DHSS 1989a), identifying the needs of their resident population and purchasing services on their behalf. Guidance from the NHS Executive in 1992 set out their responsibilities to consult local people (*Local Voices*, NHSME 1992). Through four essential activities of listening, informing, discussing and reporting, health authorities were expected to become more

responsive to the needs, views and preferences of local people in needs' assessments, establishing priorities, developing service specifications and monitoring services. However, the overriding goal of health authorities was to promote efficiency by developing and monitoring contracts and meeting budgets. Implementing the wishes of local people was secondary to this. A lack of real commitment to user participation is apparent in statements in the *Local Voices* document which indicate that gaining the support of local people could be a way for health authorities to empower themselves in making what might be unpopular decisions and that finding methods of effective consultation and involvement is a means of establishing credibility and legitimacy. In addition, the potential for health authorities to act as proxy-consumers was limited by the need to maintain stability in local health services, the lack of available alternative hospital providers and the difficulties of making meaningful comparisons between services anyway.

There was certainly an explosion in surveys and consultation activities as health authorities looked for ways of engaging people in the decision making process about planning and priorities. Health authorities sought technical and "objective" ways of assessing priorities. There were local and national surveys of the public to establish public views on health service priorities (Bowling 1996). Many health authorities set up or commissioned deliberative methods of consultation, such as Health Panels, consumer audits and citizens' juries[2] (Rigge 1995; Dunkerley and Glasner 1998; Lenaghan et al 1996). However, the voice of users was carefully controlled and the

[2] A health panel is a group of members of the public selected by quota sampling who - with the help of independent facilitators - discuss their views on topics set by the health authority (Kings Fund 2000). Consumer audits combine focus groups and in-depth interviews to identify what local people consider they need from their health care (Rigge 1995). Citizen's juries are represent ative groups of local people who meet over a number of days to address a policy or planning question (Coote & Lenaghan 1997).

exercises were placed firmly in the context of the management agenda and the task of allocating resources.

In line with consumerist principles, there was an emphasis on promoting the rights of individual users. This was done through the *Patient's Charter* which came into force in 1992, followed by a new version in 1995 (see box 4.1) (Department of Health 1991; Department of Health 1995). The *Patient's Charter* was part of the government's initiative called the *Citizen's Charter* which aimed to improve quality and standards for public service users such as students, tenants and job seekers as well as patients (Levitt et al 1995). In many respects, the *Patient's Charter* can be seen as more of a management tool than an attempt to provide users with rights. It provided health authority managers with opportunities to measure and monitor aspects of the service.

BOX 4.1: PATIENT'S CHARTERS

The Patient's Charter (Department of health 1991)

Existing rights
To receive health care on the basis of clinical need; to be registered with a GP; to receive emergency medical care at any time; to be referred to a consultant if thought necessary by a GP; to be given a clear explanation of any treatment proposed; to have access to health records; to choose whether or not to take part in medical research.

New rights
The right to detailed information about available local services, quality standards and maximum waiting times; guaranteed admission to hospital no later than two years from the day a patient joined a waiting-list; the right to have any complaint investigated and to receive a full and prompt reply from the chief executive of a trust or District or FHSA.

Standards
Requirements that trusts and health authorities should minimize waiting times for out-patient clinic appointments and the arrival of emergency services; and ensure continuity of care when patients are transferred from health to social services.

The Patient's Charter and You (Department of Health 1995)

This contained one new right and a number of new national standards. Limits were set on inpatient waiting times for specific procedures and a maximum waiting time for first outpatient appointments was introduced.

The rights and standards in the Charter were not selected in consultation with the public, were largely unambitious and had no legal force. They provided less protection than consumer rights in the commercial world. It can be argued that the lack of commitment to supporting the rights of citizens is reflected in the failure to give more powers to CHCs, and cutbacks in funding Citizen's Advice Bureaus and legal aid (Ranade 1997). In addition, although one of the goals of the Citizen's Charter was to develop effective complaints and compensation systems, it was not until 1996 that the government set up a review of complaints procedures in the health service.

Consumerist policy promoted user involvement on an individual level, albeit in a limited way because of the lack of choice available to users. The government's policy was based on faith in the power of the market to promote effective and efficient services. It was not concerned with collective forms of involvement or democracy. Henig (1994) argues that consumerist discourse has profoundly anti-democratic implications because it presents choice as an end in itself rather than as a means to politically negotiated ends, thereby effectively placing such ends beyond debate. The lack of interest in negotiation was reflected in wider social policy which sought to reduce the power of organisations which formed an intermediate tier between the consumer and state and which could therefore interfere with market process. Thus, the roles of local authorities in relation to education, housing provision and social care were reduced. All levels of the NHS were stripped of their representational components in order to allow for more efficient conduct of their business. Local authority and CHC representatives were dispatched from health authorities (Salter 1998). There was a reduction in CHC membership and their rights were reduced. CHC members no longer had the right to attend health authority board meetings and CHCs lost the right to be consulted by health authorities in relation to substantial changes to

services (NHS Executive 1990). The effect of this policy was more prominent in other spheres such as housing, education and social care where the role of local authorities had been greater to begin with (Glennerster et al 1991). A feature of the political landscape in this period was conflict between the Conservative government and Labour controlled local authorities which fought against the introduction of markets and continued to promote local participation in decision making, particularly in the sphere of housing (Sanderson 1992).

However, while there are limitations in the extent to which consumerist policy promoted involvement, the policy did put the perspective of the consumer in the frame and it was no longer possible for those in the health service to ignore it. Unfortunately, for many health professionals, the term user involvement became bound up with the notion of the over-demanding consumer. A significant development with regard to user involvement was the increase in information that was available on the nature and quality of health services. Policies that promoted managerialism gave much greater visibility to the activities of the NHS because for the first time managers were describing and measuring local health care activity and this information found its way into the public domain. This included how well services were meeting performance indicators and Health of the Nation targets. The Patient's Charter also contributed. Since 1994, the public has had access to information on the performance of Trusts in relation to some of the rights in The NHS performance Guide, otherwise known as hospital league tables. The purchaser-provider split had the result of raising the public's awareness of rationing because purchasing decisions were more explicit and showed the different priorities attached to services. These top down policies gave the public useful information to support their lobbying for more resources in specific areas.

Moving away from the market

In the final years of the last Conservative government there was a move away from an emphasis on the market. The market aspect of the reforms had not been considered a success and the focus was shifted from markets and contracts to longer term arrangements and co-operation. This reflected what was happening naturally on the ground. Health authorities had tended to maintain long term relationships with providers and had sought to involve local GPs in purchasing decisions.

A significant development with regard to user involvement occurred towards the end of the Conservative period in office. The Consumers in NHS Research standing group was set up by the NHS Executive in 1996 to provide advice on involving users at all stages of the research and development process, including the way topics are prioritised, the way research is undertaken and the findings disseminated. Some research advisory groups involved in prioritising national research areas subsequently included lay representatives (Department of Health 1999; NHS Executive 1998a).

The latest reforms

When the Labour won the general election in 1997 it set about implementing policies based on the so-called 'third way'. This signalled an approach distinct from both Conservative policies associated with market principles and the 'centralised command and control system' and tax and spend policies of the Labour governments of the 1970s. In place of the market dogma and crude individualism of the 1980s, Labour shifted the emphasis on to a more pragmatic role for the market and a more sophisticated interpretation of individualism. Some see this as a new emphasis rather than a new ideology (Heron and Dwyer 1999). The element of competition is still

there, but the focus is on the need for cooperation between mutually dependent citizens rather than individual freedom in consumerism. However, the government is not averse to forming new markets, as can be seen from the introduction of a voucher scheme for pre-school provision which enables parents of 4 year olds to "buy" nursery school care where they wish.

However, in general the policy rhetoric reflects notions of communitarianism and stakeholding, in contrast to the individualism and faith in the market associated with Conservative policies in the 1980s. There has been a focus on promoting the rights and responsibilities of citizens, local democracy and partnerships across the board in public services. The new language of citizenship is about balancing rights with responsibilities. There is a notion of 'doing your duty' as a citizen. This has been particularly pronounced in the field of social security where the responsibilities of those claiming job seeker's allowance to seek and accept work have been increasingly defined and enforced, and in education where there has been a new emphasis on parental responsibility for the behaviour of their children at school. Health policy has encouraged people to take more responsibility for their own care and to make responsible use of services, particularly GP and accident and emergency care.

In 1997 the new government published a White Paper, *The New NHS: Modern, Dependable* (Secretary of State for Health 1997). Fundholding was abolished. However, the distinction between those who pay for services and those who provide them was to remain. GP practices were to become part of GP commissioning bodies which would develop long-term service agreements with providers of health care. The commissioning function was to be undertaken by health authorities while the new Primary Care Trusts were developed. The policy, rather than being seen as radically new, can be seen as building on what was already happening. Fundholding can be

seen as the catalyst for a series of changes that were to nudge the NHS towards being primary-care led.

Aside from the changes to primary care, two themes of promoting efficiency and raising the quality of services run through the health reforms. The government was committed to increasing the funding of the health service well beyond previous levels but expected real benefits only if efficiency was also increased. Tight mechanisms of performance measurement have been introduced, backed up by the threat of central intervention if performance is found to be inadequate. There are a variety of new mechanisms to improve the quality of health care. A system of clinical governance is to integrate quality activity and promote accountability for the quality of care. There are initiatives to promote improvements in specific areas of care such as coronary heart disease. Two new organisations for promoting quality have been developed: the Commission for Health Improvement which monitors the implementation of clinical governance and investigates specific failures in services and the National Institute of Clinical Excellence which promotes, brings together and diffuses evidence about good practice.

The significance of the policy for user involvement

There has been a great deal of policy relating to user involvement. The government's policy relating directly to user involvement was spelt out in the document *Patient and Public Involvement in the new NHS* (Department of Health 1999) and in the *NHS Plan* (HMSO 2000). These documents emphasise the need for greater involvement of patients in their own health care and greater involvement of patients and the public in the way the NHS works.

There has been a move away from the consumerist policies of the past. Rights now come with responsibilities. The government replaced the Patient's Charter with a new charter in 2001 which describes what users can do to help themselves and make effective use of health services as well as delineating the rights people have. However, elements of consumerism are still evident. For example, there are plans that by 2005 patients will be offered an element of choice in the date and time of their hospital appointments and elective admissions and primary care walk-in centres have been set up in some areas to promote quicker access to general practice consultations (HMSO 2000; Department of Health 1999). In addition, the government promotes NHS Direct, a new telephone service where callers obtain health advice from nurses, as a way to improve access and choice (HMSO 2000). While NHS Direct can be seen to be more about promoting efficient use of services than promoting choice, the government's approach to selling it may reflect a wider political desire to be seen to be committed to promoting patient choice.

A significant policy development is the representation of patients or the public on new bodies on both a national and local level. On a national level, this includes lay membership of the new Modernisation Board, lay inspectors on the Commission for Health Improvement's review teams, and a new citizen's council to advise the National Institute of Clinical Excellence on its assessments of clinical effectiveness (HMSO 2000). On a local level, the boards of primary care groups (PCGs) and primary care trusts (PCTs) are required to have lay members (NHS Executive 1998b; NHS Executive 2000) and in each hospital trust, a new patient's forum will elect a member to the trust's board.

These developments could be taken to mean that the government is taking representation very seriously. However, many of the developments can be interpreted

as an attempt to address public accountability and legitimacy rather than engage the public in the decision making process. The roles of the new lay members have not been clarified. In addition, lay representation was removed from organisations within the health service in the past in part because such members were not considered to be successful at representing the views of users. It seems that the drive for accountability and openness may be overshadowing these issues and problems.

The drive to promote openness and accountability is also reflected in the promotion of openness in appointing trust board members and the new roles given to local authorities in ensuring the accountability of local health services. Local authority scrutiny committees will be given the power to refer contested major service reconfigurations to the new Independent Reconfiguration Panel (which will have patient and public representation) and chief executives of NHS organisations will be required to attend local authority scrutiny committees (HMSO 2000). In addition, the Commission for Health Improvement will open up the work of professionals to public scrutiny.

Health professionals and commissioners are expected to consult patients and other local people. The duty of health authorities to ensure public involvement in service planning activities has been re-emphasised, and PCGs and PCTs are expected to consult widely with local people (NHS Executive 1999a; Department of Health 1999). New forums for involvement are to be developed: health authorities are to establish an independent local advisory forum of residents to provide a 'sounding board for determining health priorities and policies' (HMSO 2000, p94), and trusts are to have patients' forums to provide patient input to how local services are run. However, as was the case under the Conservative government, the consultation process remains firmly under the control of health professionals, and these people have other priorities.

A difference is that in primary care the process of involvement will ultimately be led by GPs rather than health authorities. The White Paper is peppered with references to the belief that health professionals are best placed to represent patients' interests. The NHS Plan professes to strengthen patient choice and then explains that "the choices GPs are able to exercise on behalf of their patients" is important. (HMSO 2000 p89). This can be seen as part of a wider attempt to address the low morale of health care professionals inherited from the Conservative government which had been leading to high staff turnover (Rhodes and Nocon 1998). Health professionals felt side-lined by management from health service decision making in the previous system and the Reforms sought to give GPs more control.

The notion that professionals are best placed to represent the interests of the public is also evident on a national level in government policy which portrays government as the interpreter of the public's wishes and priorities. This can be considered to be a continuation of the management-led consumerism that began in the 1970s. There are so many national targets and policies with regard to specific aspects of health care, such as coronary heart disease and cancer, that there is little room left for negotiation on what matters locally. The approach addresses issues of importance to patients in a top-down way and does not automatically lead to involvement of users in the process. The formation of Health Action Zones is perhaps the main exception to this. Health Action Zones are designated geographical areas with particular problems that have received extra funding for community based projects (Department of Health 1999). It is expected that agencies will work closely with local people.

The government has put substantial emphasis on obtaining feedback from users on the health care they have received. There is to be an annual survey of NHS patients, the results of which the government intends to use to set financial rewards for trusts

(Department of Health 1998; HMSO 2000). In 1998 the government began a programme of national surveys of users. The first was a questionnaire survey of 10,000 people to assess their experience of general practice care. Similar surveys have been conducted for feedback about cancer and coronary heart disease services (Richards 1999). Providers of health care, including NHS trusts, primary care groups and primary care trusts are expected to collect feedback from patients and carers on the quality of care and services they have received (HMSO 2000). The results of their consultation exercises are to be published annually. It is not clear how the results are to inform service development and there is a danger that the surveys will amount to no more than patient satisfaction surveys.

There has been an emphasis on increasing information and promoting its accessibility. The government's Information for Health Strategy aims to meet the information needs of patients and the public by instituting new structures, standards and strategies (NHS Executive 1998c). It has set up the NHS Information Authority to promote easy access to high quality information. The National Institute of Clinical Excellence (NICE) will publish patient-friendly versions of the clinical guidelines and national service frameworks ('care blueprints') that it develops (HMSO 2000; Department of Health 1998). The National Electronic Library for Health will be more easily available and, when it is launched, NHS Direct On-line will provide access to a wide range of information on the internet. The measures are about more than consumerism: there is indication of a desire to empower patients in their health care and to promote openness. For example, the government has introduced a requirement that letters between clinicians on the patient's care will be copied to the patient (HMSO 2000).

A significant development with regard to user involvement has been the government's decision to abolish Community Health Councils - the only independent citizen-led

voice in the health service. Part of their funding is to be redirected to developing a new Patient Advocate and Liaison Service in each trust to promote a quicker response to patients' concerns and help patients make complaints. The abolition of CHCs mean the loss of an independent element. User involvement will become subsumed within the structure of the health service. On the one hand, it seems sensible that the interests of users might be better pursued if mechanisms for user involvement were better integrated with other processes in the health service, but on the other hand there is evidence that user interests can easily get lost or sidelined where health professionals control the processes.

In summary there has been a shift away from consumerism and a greater emphasis on representation and consultation, openness and accountability, partnerships between users and those in the health service, and greater access to information. However, the extent to which these changes constitute a form of democratic renewal is unclear. Health professionals continue to be firmly in control of the process and it remains to be seen how successfully the policies are implemented in practice.

The effectiveness of mechanisms for user involvement

This section describes the barriers that limit the effective involvement of users through the various mechanisms that are now available within the health service. Much of the evidence about these barriers comes from the reports and experiences of those involved or the assessments of commentators looking at the impact of initiatives. The main exceptions to this are surveys of members of primary care groups and research advisory groups.

In this section, the potential forms of user involvement are categorised into those which promote involvement on a collective level and those which promote the involvement of individual users. The public has an influence collectively through representation on groups, consultation activities and through CHCs. The influence of consumer organisations and advocacy initiatives has been described in a previous section. Members of the public have an influence as individuals through exercise of choice, rights and complaints procedures. Table 4.2 summarises the barriers to effectiveness for each type of involvement.

Collective forms of user involvement

Lay representation on committees and groups

For some years there have been user representatives on hospital trust and district level ethics committees, and on Maternity Services Liaison Committees (MSLCs). And some general practices have patient groups to advise them on such things as appointment systems and a small number of audit committees have included lay members (Kelson and Redpath 1996). In the past five years there has been an explosion in lay representation and it would be surprising now if they were not included on new committees and groups. However, there are many barriers to the involvement of users in this way. Those specifically to do with MSLCs were described in Chapter three.

Table 4.2: Barriers to effectiveness of the different forms of user involvement

FORMS OF INVOLVEMENT	BARRIERS
Representation in committees and groups	Issues to do with representation Delay in appointing user members User members' lack of knowledge, skills, information and resources Tokenism and a lack of strategy for user involvement
Consultation	Lack of commitment Consultation fatigue Lack of impact on decision making processes Inappropriate use of consultation to legitimise rationing decisions Practical and methodological barriers
Community Health Councils	Limited resources Difficulties representing diversity of local population Variation in effectiveness around country Lack of commitment within health service to consulting CHCs
Choice	Limited choices available Resistance to providing choice and involvement in health care decisions Health professionals' lack of skills and time Lack of information to make informed choices Difficulties accessing information
Rights	Under ambitious Limited to procedures (do not include clinical care) Not enforceable
Complaints procedures	System confusing and off putting Time limits on making complaints Ignores need for explanation and rectification

Issues to do with representation

Lay members of committees are assumed to be working for patients' interests as if they are all from an amorphous group with common aims and behaviours. This is a naïve position and one which ignores the different interests lay representatives may

have. Hogg and Williamson (2001) suggest that lay representatives fall into three broad categories: supporters of dominant (professional) interests, supporters of challenging (managerial) interests and supporters of repressed (patient) interests. Only the third category can be seen as likely to speak for patients' interests when they conflict with those of professionals or managers. This issue is hardly ever considered when appointing lay representatives and the cynical view could be that other members of committees seek to appoint those who agree with their position.

Delay in appointing user members

Some forums have avoided appointing lay people. There is evidence that the appointment of lay members of some Primary Care Groups has been delayed because of a preoccupation with other priorities and confusion as to what user representation means in this context (Smith and Dickson 1998; Florin 2000; Persaud 1999). Some research advisory groups and most primary care Medical Audit Advisory Groups and trust Clinical Audit Groups exclude user members because of professional members' concerns about how unrepresentative such a member would be and the danger that they would identify different and incompatible priorities to those identified by themselves (NHS Executive 1998a; Kelson and Redpath 1996).

Skills, information and resources

Users are restricted in their efforts to be involved by limitations of knowledge, skills and resources. They need to have an understanding of the health service and its organisations and how and where decisions are made (Brownlea 1987). The high rate of organisational change makes it difficult to keep up to date. Most members of the public do not know what primary care groups are or understand what clinical governance means (Florin and Anderson 2000; Levenson 2000). They need skills to attend and run meetings and the ability to communicate with people from

professionals backgrounds. Technical skills required include the ability to understand scientific terminology and jargon (Brownlea 1987; Beresford and Croft 1993). User involvement has resource implications: meeting places, administrative support, traveling and childcare expenses, and training (Rigge 1999). There is no central provision for the funding of such expenses even though such support is considered vital to promoting user involvement (Hanley 2000).

Problems within the committee

User representatives have complained about tokenism and isolation (Rigge 1994; Liberati 1997; NHS Executive 1998a), particularly where there is only one user member (Kelson and Redpath 1996). The capacity for a single lay member to be able to somehow represent or speak for a community is severely limited and yet frequently only one such member is included (Smith and Dickson 1998). Tokenism is a danger when the role of the user member/s has not been properly clarified and there is no support or structure for them to work within. There is concern that these problems will surface in the new Primary Care Groups as there is presently no conceptual, managerial or financial infrastructure for public involvement through these groups (Fisher et al 1999; Johns 1999; Kelson and Redpath 1996). User representatives on research advisory groups setting national research priorities found them inhibiting and were not convinced they were an appropriate way of involving users (NHS Executive 1998a). In general, user members have found that when they do challenge dominant interests they are accused of unrepresentativeness (Bould 1990).

Health professionals have been resistant to user participation in the committee or group because they do not see what patients could possibly contribute and because of concerns about the confidentiality of staff (Rigge 1999).

Consultation

There are two types of consultation activity in the health service: activities such as surveys of patients for their views on the quality of services they have received, and activity where patients or members of the public are asked for their views on the health service and local and national priorities. There are several barriers to the implementation and impact of both types.

Lack of commitment

The extent to which the activities of health authorities have conducted adequate consultation activities appeared to be limited. An evaluation for NHSE in Spring 1994 showed that only 21% of health authorities had been found to consult widely, assess the impact of findings and adequately report back to the public on the outcome (HSJ 1995).

Consultation fatigue

Health authorities are required to consult in so many areas that they do not have the flexibility to focus on local needs driven consultation. For example, among many things, they are expected to obtain the public's response to the commissioning strategy, commissioning intentions for the forthcoming year and the annual public health report. In addition, the community-based needs' assessments they conduct often involve an element of public consultation (Adam and Gill 1994). The existing requirements are such that health authorities and the public are in danger of consultation fatigue and the new requirements will only add to the load (Coote 2000).

Lack of impact

There is concern that consultation activities do not have a significant impact on the decisions made about how services should be developed (Pickard 1998; Edwards 1996; Harrison and Mort 1998; Milewa et al 1998). At best, the impact of citizen's juries has been to add weight to the importance of issues that commissioning bodies already considered priorities (McIver 1996). To some extent the lack of impact is due to the fact that much of the health service is set by national policy and central directives and there is little local flexibility to develop services differently. The lack of influence available to users is particularly pronounced in consultation exercises to do with major changes of services. In this case it is the Medical Royal Colleges that have the most power to determine patterns of local services, by withholding or otherwise their approval of training and consultant posts in hospitals (NHS Confederation 2000). Health authorities have been criticised for not being honest about the real contribution the public can make through the consultation process.

At the same time, health authorities have been criticised for showing a lack of commitment to user involvement where it could have an effect. Health authorities have been found to reject a structured and systematic approach to local participation in favour of a far more malleable, flexible approach that they can apply selectively (Milewa et al 1998). It is rare for the findings of consumer audits to be incorporated into the clinical audit cycle to inform the setting of standards and citizen's juries have been criticised for having little or no influence on the decisions made by those who commission them (Powell et al 1994; Pickard 1998).

The government intends that the results of new national and local surveys of users will help to identify areas that require improvement, but it is not yet clear how this will come about. Critics report that so far the national survey has not generated any useful

comparable performance data and it remains unclear how patients' views gathered in local surveys will be analysed by trusts (Gilbert 2000). The overall aim of these exercises is unclear and it has not been stipulated how the mechanisms should integrate with other measures to do with quality assurance and clinical governance (Coote 2000; Gilbert 2000).

Inappropriate use of consultation

There is concern that consultation exercises are used as a way of legitimising decisions about service changes which health authorities have already decided to make or as a way to establish public tolerance for reducing or reconfiguring services (Harrison and Mort 1998; Edwards 1996). An objection to citizen's juries is that the exercise merely equips members of the public to think like NHS managers (NHS Confederation 2000).

It has been suggested that consultation about service priorities could lead to discrimination against minority groups (Doyal 1998). People tend to prioritise treatments for younger rather than older people and give lower priority to people with self-inflicted conditions and mental illnesses (Bowling 1996; Groves 1993). Critics consider this use of consultation to be unethical as it obscures some highly contentious social and ethical questions and is at odds with the NHS principles of equity and comprehensiveness (Pfeffer & Pollock 1993; Doyal 1995, 1998). Concern is heightened by research which shows that how respondents rank priorities for the health service is amenable to manipulation by changing the amount of information given and the way questions are phrased (Levitt et al 1995).

Practical barriers

There are many practical barriers to both types of consultation. Gaining access to some sections of the community is difficult. Techniques that rely on a small number of participants are open to the charge that they are not representative of the local population even if sampling techniques are used (Pickard 1998). Consultation is time consuming and requires resources and skills that might not be readily available (Rigge 1995). In addition, the public is often very sceptical about the motivation behind consultation exercises and therefore reluctant to be involved (Robinson and Whitmore 1996).

Methodological barriers

There are also methodological barriers. Patient satisfaction surveys have been discredited to some extent in that respondents will report a high degree of satisfaction despite having fundamental concerns about the care they received (Staniszewska and Ahmed 1999). They have been used for public relations purposes rather than as an opportunity to identify problems with services or assess clinical care. They have been criticised in the past for not asking patients about the quality of their clinical care. The recently introduced national surveys can also be criticised for this reason as they focus on topics such as access to services and waiting times rather than the nature and quality of clinical care (NHS Executive 2000).

More systematic and open processes have also been the subject of criticism. Citizens' juries are prone to bias from many sources including how the information is transmitted to jurors, how the moderator inadvertently sways their deliberations and how discussions are influenced by the group's internal dynamics (Dunkerley and Glasner 1998; Lenaghan et al 1996).

Qualitative methods have been identified as particularly suitable for finding out users' views on the quality and effectiveness of health services and for identifying patient based outcome measures (Powell et al 1994) and their use has been endorsed by the Royal College of Nursing (Cunningham and Waters 1997); but there is an ingrained scepticism about qualitative methods in the health service, particularly in the medical profession. Health care professionals prefer to use standardised measures, such as quality of life assessments which, though useful, do not reflect the individual patient's priorities (Staniszewska 1999).

Community Health Councils (CHCs)

CHCs are included in this section despite their impending demise because they were in place during the study fieldwork and currently still exist. CHCs were developed to represent the interests of the public in their districts and give consumers an accessible mechanism for voicing concerns about the NHS. They combined helping individual users with engaging the wider public in the planning of local health services. Klein describes how their power consisted of the ability to throw grit into the normal machinery of NHS decision-making (Klein 1995). They could impose delays because any decisions on closures not approved by CHCs had to be referred to the DHSS.

Since their introduction there has been ongoing debate about the role and effectiveness of CHCs (Klein 1990). They have been criticised for duplicating work done by health authority members, for not being constructive in their relationships with health professionals and the health authority, and for failing to represent the full range of views in the local population (Coote 2000).

There has certainly been great variation in the work done by CHCs (Dabbs 1999). They have limited resources and have to decide where best to focus these. The extent to which health authorities involve CHCs has varied. For example, less than half of London CHCs were involved in devising local patients' charters (Joule 1993). People in CHCs recognise there are weaknesses, but consider them to be important because they are the only independent form of user involvement within the health service and also because they provide an important public service by disseminating information to local people and helping them when they want to make complaints (Manero and English 1999, Lawes 1999). There is concern that without CHCs there will be a fragmentation of the user voice in the health service as there will no longer be a 'one-stop shop' available to the public (Gilbert 2000).

Individual forms of user influence on health care

Choice

Choices are available in two areas of the health service. The public has been given some choices over the services it can access and there has been a growing emphasis on the involvement of patients in decisions to do with their treatment or care. However, the ability to exercise choice in both ways is affected by the behaviour of health professionals and the availability and nature of information.

The behaviour of health professionals

In theory, users have some choice of which GP to register with and can ask for a second opinion to do with their secondary care. However, in practice, some people have found it difficult to change GPs and to get their GPs to refer them for a second opinion regarding their consultant care.

The involvement of patients in decisions relating to their health care is dependent upon the commitment of health care professionals to this course of action. Some are resistant to this. For example, a study found that the resistance of doctors to self-management schemes and self-help groups meant that they did not tell patients about their existence (McIver 1999). In addition, staff can shape a patient's views by placing emphasis on certain benefits or risks depending on which course he or she believes to be best (Alderson 2000). Where they do want to engage patients more in health care decisions, staff may be lacking the necessary skills and confidence (Staniszewska 2000; NHS Executive 1999b). Having the necessary time is also a factor. In the average eight minute consultation it may be difficult to determine patients' preferences and sensitivities and provide full and unbiased information (Coulter 1999).

Information

The paucity of information currently available to inform decisions about which GP to enlist with or which consultant to see means that people have no option but to rely on the view and judgement of professionals in this matter. The government has plans to publish information about each general practice including list size, accessibility and performance against standards in the national service framework (HMSO 2000), but there will be no information about the quality of care and communication skills of individual GPs.

Users face obstacles accessing and appreciating information that is available about their condition and treatment. NHS Direct On-line and other information on websites is only available to those who have access to the internet. There may be problems with the consistency and quality of the information provided (Staniszewska 2000). Finally, it may be difficult for an individual to assess the relevance of the information they do find

to their own case and this could lead to unnecessary anxiety (Royal College of Surgeons 2000).

Rights

Patients have been assigned rights but these have been criticised for being under-ambitious (Dillner 1991), for focusing on rights of access which are not generally in question, and on procedures rather than the content or quality of care. The process of development of the rights has been criticised for not including users.

There is no independent monitoring of how well the rights are implemented and no body to investigate failures to achieve rights. User and patients' organisations are suspicious that their rights are being eroded (McIver and Martin 1996). Open access to patient records is still not the norm and may be further discouraged by the introduction of computerisation which makes bedside records obsolete (Staniszewska 2000). The rights as defined in the Charter are not legally enforceable - the only recourse is to complain and there have been high profile cases where the right to care on the basis of clinical need has been overridden. New rights of redress for cancelled operations are to be introduced but it remains to be seen how they benefit patients (HMSO 2000).

Complaints procedures

The health service was slow to improve complaints procedures and introduce a more independent element. In 1973 users had been given the option of complaining directly to the Health Service Commissioner concerning failures in provision of services and incidents of maladministration by health authorities (Levitt et al 1995). In 1981,

patients were given the right to take their complaints to the Regional Medical Advisor if they were not satisfied by the response of the consultant or health authority manager. If this failed they could then request an independent professional review panel (Levitt et al 1995). As a result of a review in 1996, procedures across community and hospital services and general practice were standardised were standardised and the powers of the Health Service Commissioner were widened to include complaints about the clinical judgement of doctors (Levitt et al 1995). It was also determined that independent professional review panels should have a majority of lay members. The new system was designed to be speedier, less adversarial and easier to navigate.

Complaints procedures have been improved but there continue to be problems. Some of these are bureaucratic. A study found that many people were put off complaining by confusion about the procedures for making a complaint (Winkler 1993). A barrier to complaining about GPs is the three month time limit within which a complaint has to be made following the alleged failure of care. The decision on whether to hear complaints submitted after this time rests with the health authorities and doctors concerned. Patients can complain to the Health Commissioner, but during a 17 year period only 16% of such complaints were investigated and reported on (Levitt et al 1995). Others were excluded because they did not fall under the remit of the Commissioner.

Concerns of patients are often unheard because, while they have grievances, many do not wish to pursue a formal complaint or are too intimidated by the prospect of coming face to face with the health professionals concerned. There is also criticism that the complaints system focuses too much on establishing blame and does not accommodate the patient's need to be given an explanation of what happened and reassurance that any necessary action will be taken to rectify the situation. The extent

to which complaints are seen as a source of information on the effectiveness of the heath service appears limited.

There are reports that the public has no confidence in the complaints system nor in the capacity of the medical profession to regulate itself regarding malpractice (Smith and Dickson 1998; Smith 1998; Savage 1998). This has been demonstrated by the increase in the number of patients pursuing malpractice claims through the courts, despite difficulties obtaining redress in this way in the United Kingdom (Seale 1993). There have been calls for a more independent complaints system within the health service and a more independent voice within the medical profession's own disciplinary procedures (Winkler 1993; Savage 1998). The government has recently expressed concerns about the problems facing complainants and the public's loss of confidence in the professional regulatory bodies (HMSO 2000), but it remains to be seen what changes are made as a result of their reviews.

Assessment of user involvement in the health service

There has been a shift from the position where users were seen as having only a passive role with regard to the health service and their health care to one where they expect to be involved and where those within the health service actively seek their views (Milewa et al 1999). However, there are multiple forces behind the growth of user involvement and a concern to empower users and promote participation have not always been the primary objectives.

Commentators have identified two different philosophies or motivations which have underpinned the development of user involvement: consumerism and humanitarian or democratic concerns (Barnes and Wistow 1992; van den Heuvel 1980, Hoggett and

Hambleton 1987). Changes in society in general and citizen-led initiatives such as user groups have been heavily influenced by humanitarian concerns. They have sought to protect rights and promote the autonomy of people using health services.

Health policy, on the other hand, has been more concerned with consumerism, particularly in the 1980s and early 1990s. The focus on users was as individual consumers with concerns about choice, access, information, rights and complaints procedures. A fundamental difference between consumerism and humanitarianism is that consumerism is not in essence about participatory democracy or shared decision making and does not directly address the accountability of health professionals to the public. The principles of consumerism were based on economic theory rather than a model of user empowerment (Potter 1988). Van den Heuvel (1980) argued that user involvement in the context of consumerism was about controlling costs and promoting efficiency. The previous section on user involvement in the health service looked at how the motivation to control costs has been an overriding interest of politicians. The contrasting interests of users concerned with empowerment and of policy makers in the health service concerned with cost containment has led to conflict because as Croft and Beresford (1990) observe: "'The politics of liberation don't necessarily sit comfortably with those of the marketplace".

An emphasis on consumerism in health policy relating to user involvement is still present although since the Labour victory in 1997 there has also been a great deal of policy rhetoric focusing on the patient as an important definer of quality of care, the need for 'partnerships' between health professionals and the public, and the benefits of user empowerment and education (Coulter 1999). The relationship between users and those in the health service now seems to be based on a mix of consumerist and

citizen's values (Patient's Assocation 2000). However, it is not clear that the new policies will promote participation and empower people in practice

In practice it is not always easy to distinguish the motives behind user involvement policy. The same terminology is used in both approaches, although it may imply very different things. For example, from a consumerist perspective the term "choice" may reflect an interest in giving patients a choice of GP or time of appointment, whereas from a humanitarian perspective it may reflect a wish to promote autonomy in the clinical encounter and the need to involve patients in clinical decision making about which treatment they receive.

There are now a variety of mechanisms through which the user voice is heard. However, in general, user involvement through these various mechanisms amounts to consultation rather than participation and falls short even there (Pollitt 1989). The public have been involved more as targets of health care than as reformers. There is little evidence of the more participative options for user empowerment described by Coote (1993). There is no democratic representation, there has been no issue voting and there is little evidence of negotiation between users and professionals. An exception may be health action zones which reflected the need for professionals to work within the community in collaboration with local people.

Maxwell and Weaver describe five activities that fall within the definition of public participation, reflecting increasing degrees of user involvement: consumer protection, public consultation, openness of managerial decision-making, full management participation by public representatives, and heightened individual and community responsibility and power (Maxwell and Weaver 1984). Certainly there is a focus on consumer protection through improving complaints procedures, clarifying patients

rights and the governmental pressure on the medical profession to better regulate medical practice. Consultation is a continuing feature of the NHS although its impact is limited and recently, there has been a focus on openness in decision making. However, there is little evidence of full participation by lay representatives and the power to plan health services and define health care still rests firmly with politicians, managers and GPs.

In a study of participation in health, education and pensions, Papadakis and Taylor-Gooby (1987) distinguished three forms of potential participation: choice, voice and control. Users in the health service have a limited degree of choice and various mechanisms for expressing their views but health professionals have control over what and how choices are offered and what weight they give to users' views in consultation exercises.

Those who are not satisfied with the extent of involvement have described the lack of adequate representation and input to decision making as a 'democratic deficit' (Cooper et al 1995). They lament the lack of adequate forms of representation (Joule 1993; Pollock 1992). The new focus on participation and partnerships offers some hope, but there are major obstacles to overcome. However, the barriers that have shaped user involvement and will continue to do so reflect three fundamental features of the health service and users which are not easily changed: the structure and policies of the health service, the degree of professional dominance that exists, and the characteristics of users themselves.

The structure and policies of the health service

The evolution of the relationship between users and health professionals within the health service is highly dependent upon developments in health service policy and organisation (Milewa et al 1999). It can be argued that the structure and policies of the health service reinforce a non-participative approach to user involvement. Primary care groups and trusts are accountable to health authorities which are in turn accountable to the government and the views of local people are overtaken by political, statutory and bureaucratic requirements. Rhodes and Nocon argue that in its zeal to court professionals' goodwill, the government's policy of GP commissioning may have inadvertently opened the door to a return to professional paternalism. They explain that the Government seems to have forgotten that the critique of professional paternalism and unresponsiveness originated not only from the political right but had a long-standing history on the political left and was primarily initiated by service users themselves (Rhodes and Nocon 1998).

Current government policy states that user involvement should not be an add-on (HMSO 2000), but management and quality assurance processes can go on without it and the absence of a specific strategy for how user involvement should fit in with clinical governance will make this difficult to change (Gilbert 2000). There is already concern that health professionals put clinical governance and involving users in separate boxes (Levenson 2000). For most Primary Care Groups the reality is that other corporate priorities such as setting up infrastructure have predominated (Florin and Anderson 2000).

The quality agenda is firmly set by central government and this, combined with the high degree of central command in general, reduces local flexibility to focus on issues

of local concern. In this context, consultation exercises and representation take on elements of theatre (Milewa 1997). Health professionals are put in a position of acting as if users can have an influence on decision making when in fact this is far from the reality of the situation. User involvement initiatives are subsumed within bureaucratic structures where other priorities can easily take precedence. Perhaps this reflects a lack of confidence among policy makers that users can make a contribution on a higher level.

In addition, although it is argued that people have become more sceptical about the ability of science and expert knowledge to have answers to important questions (Biggs 1997), health services are still planned largely from a technocratic perspective which reflects a high degree of faith in the abilities of science, and this approach tends to sideline user participation (Sanderson 1999). For instance, for some years the essence of policy in relation to quality has been the promotion of evidence-based practice. This can be seen primarily as a political move that attempts to off-load governmental responsibility for rationing rather than a deliberate effort to restrict the input of users; however, the approach veers away from public debate and implies it is not necessary. In practice, issues of rationing have not been so easily obscured and the government has had to make pronouncements on the availability of interventions, as was the case with the drug Viagra.

Organisational culture is resistant to public involvement. The NHS tends to behave as an inward looking and secretive organisation. Existing systems for collecting and managing information are not well suited to open government or to public involvement (Kings Fund 2000). Levels of secrecy shot up with the advent of the internal market and still endure to some extent because of the continuing emphasis on competitiveness and the punitive use that may be made of unfavourable information.

Policy with regard to user involvement has reflected a consumerist rather than a democratic or humanitarian perspective. The recent reforms emphasise the need for partnerships and greater involvement, but in general the bureaucratic structure of the health service is still more concerned with the responsiveness of services to the public rather than involving people in developing services. Recent health reforms have ensured there is lay or patient representation in the new structures and organisations, but it is not clear that they will be able to promote participation or even that this is what is expected by those involved. It can be argued that the increase in representation reflects consumerist rather than democratic philosophy. It can be seen primarily as an attempt to promote legitimacy and accountability in the face of public dissatisfaction with the health service rather than public or patient participation. Policy documents are conspicuous for the absence of details as to how the input of user representatives should influence decisions and seem to be ignoring the problems users have experienced on such forums before. Wall considers that widening health authority and trust representation suggests muddled thinking about the nature of representation and accountability in the NHS and is a throwback to unsatisfactory arrangements prior to 1991(Wall 1997).

Health policy has been very prescriptive with regard to the structures that should be in place for user involvement. This reflects the wider situation with health policy and with social policy in general where for several decades there has been a high degree of central command. Within this context the policies which specify what types of forum should be present locally for user involvement do not seem unusual. However, there is the question of how well these top-down policy requirements actually reflect what users want. For example, people may not want to be treated as consumers when it comes to public services. There is evidence that users lack both the knowledge and

inclination for making market-like choices between different providers such as GPs (Charny et al 1990; Shackley and Ryan 1994, 1995). In addition, there are also fundamental concerns about the impact of consumerism on equity, a fundamental principle behind the health service to which most people are committed. The public has little or no control over fundamental changes to the way its voice is heard. CHCs were set up many years ago to represent the public by one government and are about to be abolished by another; and yet it is not clear that the new patient liaison services within trusts will provide the same degree of protection. There is a danger that the structures within the health service expected to replace the functions of the CHC will individualise and therefore dilute users' concerns.

This begs the question of whether users can influence the policy making process and to what extent. A pluralistic approach to policy analysis might suggest that users as much as any other interest group have the capacity to influence the shape of health policy and therefore user involvement policy. Pluralists would argue that power is widely distributed among different groups and that no one group is automatically dominant (Ham 1999). However, when applied to user involvement policy this does not accommodate the high degree of professional power that exists in the health service and how this has moderated the influence of user interests. A structuralist approach helps to explain the problem because it distinguishes between dominant, challenging and repressed interests (Alford 1975). Dominant interests can be seen as those of doctors, challenging interests can be seen as those of managers and policy makers, and the repressed interests can be seen as the public. Obtaining a level of influence in such a context would be extremely difficult.

Professional dominance

There is a high degree of professional control over user involvement in the health service and up until recently, government policy has tended to safeguard medical autonomy. For example, the policy introducing medical audit explained that 'the quality of medical work can only be reviewed by a doctor's peers' (Department of Health 1989). Medical audit was not compulsory and seen as a professional exercise. Managers were supposed to have access to aggregated results but had difficulty gaining access. Since this time, policy has sought to better integrate medical audit with that of other disciplines and with wider quality assurance and contracting, and has indicated that there should be a stronger focus on the patient (Department of Health 1993a) and has made clinical audit compulsory. This may have achieved greater managerial involvement but user input has been limited.

Klein has written of a continuum of user involvement from professional dominance to consumer dominance, moving from information provision or consultation, through negotiation and participation to the power of veto (Klein 1975). On this continuum, user involvement in the health service falls towards the professional dominance end. In the United States, Arnstein conceived a typology of eight levels of participation arranged in a ladder pattern with each rung corresponding to the extent of citizens' power in determining the end product. Lower rungs, such as manipulation, reflect non-participation; middle rungs of informing, consultation and placation reflect degrees of tokenism; and the upper rungs of partnership, delegated power and citizen control signify degrees of citizen power (Arnstein 1969). User involvement in the health service includes informing, consultation and placation - activities reflective of tokenism; and there is also evidence of manipulation (Arnstein 1969).

Critics believe that the commitment to fostering public and patient participation that could exist is compromised by the self interest of health authorities and health professionals (Sang 1999). Policies may promote a high degree of participation and extol the virtues of partnerships, but implementation of these ideals is dependent upon those in the health service. Committees and groups such as Primary Care Groups and audit groups have delayed the inclusion of lay representation. Activities such as citizens' juries make the process of consultation more systematic and open to scrutiny, but have little or no influence on the decisions made by those who commission them (Pickard 1998). The public is consulted over changes to local hospital provision, but in practice has little or no influence (NHS Confederation 2000). Within the clinical encounter health care professionals have the potential to influence the outcome of the consultation in many ways.

Thus user involvement is shaped by the agendas and concerns of health professionals. Professional leaders are now more likely to extol the benefits of patient involvement, for example, the Royal College of Nursing promotes patient involvement in local audit and guideline development (Kelson 1999; Staniszewska 2000), but progress beyond this point is slow (Rajasekar and Brigrigg 1999; Kelson and Redpath 1996). Doctors in particular have been slow to appreciate the benefits of involving users, particularly in research, evaluation and audit (Kelson 1995). Users are not usually involved in these activities despite recognition in some quarters that outcome measures defined by users can provide a better and more comprehensive assessment of care than clinical outcome measures on their own (Avis 1997; Entwistle et al 1998). Progress is hindered by the medical profession's concerns that users tend to focus on the quantity rather than quality of interventions and may want interventions or treatments which are not effective (Wiles 1993; Hopkins et al 1994).

Changes in society have led to a less subservient and more questioning user who seeks more involvement in health care. However, there is always a danger that health professionals try to redraw boundaries between themselves and users to avoid the uncertainty that is associated with the shifting roles of professionals and users (Biggs 1997). New policies may encourage partnerships and negotiation, but these are likely to be stressful, messy and complex processes. A retreat to the greater certainty and control associated with paternalistic or technocratic decision making is understandable.

Characteristics of users

Users are held back in their efforts to be involved on an individual or collective basis by a lack of knowledge, skills and resources, and difficulties with access. To become informed about their health care they need to be able to access information that is available and be able to understand its relevance to them. To function effectively as lay representatives on committees and groups they need personal and technical skills and an understanding of the health service and how it works.

The capacity of some individuals to take advantage of choices and be involved in consultation exercises or as lay representatives is limited by problems to do with access. People from disadvantaged sections of the community are less likely to use some services and less likely to put themselves forward as representatives.

Finally, not all users want to get involved. For example, there has been found to be a generational difference with regard to whether patients want to get involved in decisions to do with their treatment, with younger people more keen to be engaged in the decision making process (Guadagnoli and Ward 1998; Charles et al 1998).

Conclusion

Growing disillusionment with medicine and changes in the way people relate to those in authority have led people to be less passive in relation to matters of health on an individual and collective level. However, user participation in decision-making in the health service has to a large extent lagged behind public expectations. It has been hindered by competing forces in the structure and policies of the health service and a high degree of professional resistance. In general, health policy has been more concerned with controlling costs and promoting efficiency than ensuring users have a real say in decision-making processes. Recent health policy has strongly emphasised the government's commitment to improving patient and public involvement, but it remains to be seen how much is achieved. It is clear that there are formidable challenges.

An increase in lay representation on committees and groups is a significant feature of the new policy and yet there is little guidance on how to ensure this translates into real involvement. While there have been surveys of structure and anecdotal reports of problems in committees and groups, very little is understood about their processes and the interaction between members, and therefore the potential for user involvement. This study seeks to address this deficit through investigation of Maternity Services Liaison Committees - one of the most longstanding committees to include lay representation. The problems they experience will provide a guide for likely difficulties that will be experienced in other committees and groups.

Chapter five:

The study methodology

This chapter describes the methods used in the study to assess the effectiveness of MSLCs. The first section looks at the rationale behind the qualitative approach taken. The next section describes how the samples of MSLCs and interview respondents were chosen and how the observation and interview data were collected. This is followed by an explanation of how the observation and interview data were organised and analysed. Ways in which the trustworthiness of qualitative studies can be promoted and the relevance of these approaches to this study are then discussed. Finally, the characteristics of the study MSLCs and interview respondents are presented.

A qualitative approach

This is a qualitative study of the effectiveness of MSLCs using a combination of observation and interview methods. Qualitative methods are useful for evaluating process, exploring complex behaviours, attitudes and interactions which are not amenable to quantitative research (Patton 1987; Pope & Mays 1995). They are particularly oriented toward exploration, discovery, and inductive logic (Patton 1990). These benefits are pertinent to this study because although the work of other researchers has provided some information on the structure of MSLCs and the views of members (mainly users), there is no systematic information available on what MSLCs actually do and how members interact. In fact, very little is understood about the dynamics of joint working between users and health professionals in any context. Given the lack of knowledge, the study does not set out to test pre-specified hypotheses or ideas about how MSLCs work. The one exception to this open approach

was that a decision was taken to adopt a one-year observation period in order to establish the involvement of MSLCs with the annual planning and monitoring cycle of health authorities and trusts.

The main approach taken in the study is one of observation. Observing the committees and getting to know the people involved was considered an important way of developing an understanding of the environment and what people bring to it. Observation is a method well suited to researching 'human meanings, interpretation and interactions, where the phenomenon under investigation is generally obscured from public view; where it is controversial; and where little is understood and it may therefore be assumed that an "inside" perspective would enhance existing knowledge' (Waddington 1994, p108). As a phenomenon, MSLCs are particularly suitable for observation because their main activity is circumscribed in the form of regular meetings.

A fourfold typology is often used to distinguish between types of observation (Gold 1958). This distinguishes between the complete observer, the observer as participant, the participant as observer and the complete participant. The author aimed to be a 'complete observer', someone who merely stands back and 'eavesdrops' on the proceedings. (The author was not eligible for any form of membership so a more participative role was not possible.) However, there are several dimensions of observer behaviour which cut across this typology and in relation to which an observer has to consider their position (Atkinson and Hammersley 1994). These include the extent to which the observer intends to be an insider or outsider, how well they and their intentions are to be known about, and how much they intend to engage with what is going on. The behaviour of the author on these variables may signify a greater degree of involvement with those in the field than may be expected from a 'complete

observer'. The author intended to seek contact with members where possible outside meetings and during meetings (talking before the start of meetings and at the end) and saw building up relationships with those in the field as important to the research. It was important to be seen as sympathetic to and interested in all points of view and to appear non-judgemental. The author did not attempt to be inconspicuous or avoid being open about the purpose of her presence. It was made clear to all MSLC members that the author was a researcher investigating the effectiveness of MSLCs. With regard to engaging with the committees, the author was committed to feeding back the results of the study at the end of the observation period in the form of a report. This expectation was an outcome of the 'negotiation' that took place during the recruitment phase of the study and reflected the intention that MSLCs should benefit in some way from being involved in the study. In addition, there was a separate 'negotiation' with three chairpersons who wanted feedback on their chairing skills.

The principles of stakeholder analysis inform the approach taken in the study. Stakeholders can be defined as actors, agents, or interested parties. From the theoretical point of view, stakeholders are of interest because their needs, wants, desires, perceptions and conceptualisations are different. Stakeholder analysis accepts the subjective nature of reality and expects that different stakeholders will experience the 'same' phenomenon differently. It therefore favours a constructionist (rather than realist) and pluralist (rather than unitary) view of reality (Burgoyne 1994). It understands that situations are not necessarily the manifestation of single purposes or plans, but are created by the interaction of multiple purposes and agendas.

This approach has been missing from previous research into MSLCs, which has focused on their structure and has looked at them mainly from the user perspective. The approach acknowledges the need to take into account the views of *all* those

involved in MSLCs to understand what MSLCs do and can achieve. It seems appropriate to see MSLCs in terms of the interaction of different stakeholding groups whose different (or similar) perspectives influence the nature of MSLC meetings and the interaction between members. Stakeholder analysis is interested in the manifestation of 'cultural software' that actors have internalised (Burgoyne 1994, p189). This translates into the assumption that factors to do with the background and motivation of members from different stakeholding groups will be more relevant to the functioning of the committees and members' views on effectiveness than differences in members' personalities or aspects of the ways in which groups generally function. The main stakeholders in MSLCs can be identified as users, health care professionals and health authority managers. However, the intention is not to let this simple categorisation blind the author to differences within stakeholding groups or similarities between different groups. As Burgoyne has written, identifying stakeholders in a particular situation can itself be an empirical process (Burgoyne 1994). Interviewing MSLC members is an important mechanism by which the views and perspectives of different stakeholders will be sought.

The study aims to elucidate the nature of user involvement and identify what shapes it. It is distinguishable from a programme evaluation in that it does not set out to make judgements about the overall merit of the programme (in this case, MSLCs) for policy or decision makers and the parameters of the study have not been negotiated with policy makers or members of any interest group (Greene 1994). Patton states that 'when one examines and judges accomplishments and effectiveness, one is engaged in evaluation' (Patton 1990) and this study would seem to fall within this definition, but he goes on to explain that evaluation research is judged by its usefulness in making action and interaction more effective and its practical utility to policy makers. This study uses policy guidance on MSLCs as a yardstick for comparison of the study committees

- but it is not a main aim of the study to map MSLCs in relation to this policy or to make suggestions for how MSLCs should be changed. The purpose of the study is to understand user involvement in the social context of MSLCs and establish its relevance to user involvement in the health service more generally.

Combining observation and interview methods provides several benefits. It allows respondents' views to be understood in the context of the work of their MSLCs and the behaviour of members. Background knowledge of what happens at meetings and how the member behaves on the committee enables interview questions and prompts to be tailored to the individual respondent. It also allows the study to look at how respondents' views on what goes on in the committee correspond to what is observed.

Sampling the MSLCs

A purposive sample of MSLCs was chosen to provide maximum variation on characteristics likely to be relevant to their functioning and effectiveness. The aim was to identify a sample containing a wide range of different MSLCs in order to appreciate their full range of activity and the full variety of influences on how they work. With qualitative sampling the intention is to include a sufficient range of cases to ensure confidence in conceptual generalisations (Patton 1990). The number in a sample is based on the variation in features in the population and the need to be able to identify any common patterns which cut across this variation. The greater the variation, the larger the sample will need to be, but the number will also be influenced to some extent by practical constraints.

Three sets of dimensions of MSLC structural variation were considered likely to affect the functioning and effectiveness of MSLCs. They are shown in box 5.1. The survey

conducted by the *Changing Childbirth* Implementation Team in 1996 provided a sampling frame for the study since it supplied information on the structural features of well over a hundred MSLCs.

BOX 5.1: SETS OF SAMPLING CRITERIA	
MSLC relationship with outside organisations	Accountable to the health authority or hospital trust Covers one or more hospital trusts
Within-MSLC structural features	Chaired by lay person or health professional Size of membership Meeting are four or six times per year
Remit	Whether or not MSLC reported a remit to do with clinical guidelines / audit

Relationship with outside organisations

MSLCs have different accountability arrangements: some are accountable to health authorities, some to hospital trusts, and a small number are accountable to both health authorities and trusts. Those accountable to health authorities might be expected to have a more strategic focus than those accountable to hospital trusts. Policy guidance on MSLCs has recommended that they should be accountable to health authorities and many have changed in accordance with this. However, the survey of 1996 showed that there continued to be a large number of committees accountable to hospital trusts and as it was not certain that these would change their arrangements, both types have been included in the study. The study did not set out to include a MSLC accountable to both a health authority and trust, but in practice one of those included in the sample on the basis that it was accountable to a health authority turned out to have this set up.

The second distinction was with regard to the number of hospital maternity units the work of the MSLCs covered. MSLCs accountable to health authorities are distinguishable by whether they cover the work of one or more than one hospital trust. Those MSLCs with health care professionals from more than one unit might be expected to be influenced by issues in the relationship between clinicians in different units so it was decided to include both types in the sample.

Within-MSLC structural features

Secondary sampling criteria were those that could be expected to influence the process of MSLCs: whether the MSLC was chaired by a health professional or a lay person, the size of the committee, and how frequently the committee met. While policy guidance indicates that MSLCs should be lay chaired, the 1996 survey found that many committees were still chaired by health professionals and so it was decided to include this type in the study. With regard to committee size, the 1996 survey found wide variation and the aim of the study was to ensure the MSLCs in the study reflected this variation. Finally, the survey showed that the majority of MSLCs met either four or six times per year and it was decided to ensure the sample included MSLCs with both these arrangements.

Remit

Little is known about the work of MSLCs. The 1996 survey asked one question about remit and found that some MSLCs did not report a role in relation to clinical guidelines and clinical care (see chapter three for more details). While this was not considered a very reliable source of information on the work of the MSLCs because there was no detail as to what the work amounted to and many MSLCs had noted on the

questionnaire that their remit was in the process of re-development, it was decided to enroll one MSLC that reportedly did not have a remit to do with clinical matters.

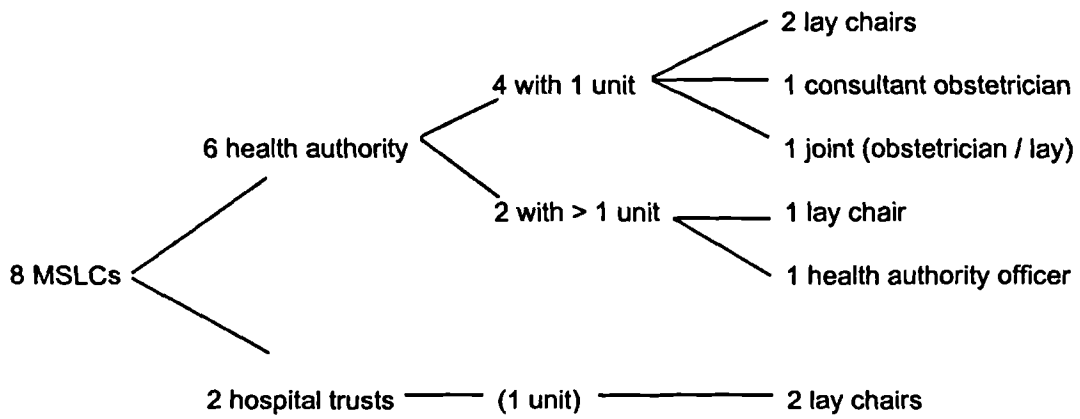
Choosing between MSLCs meeting the eligibility criteria

Where a choice would have to be made between MSLCs equally eligible for inclusion based on these criteria, it was decided to choose committees in districts that varied according to whether they contained teaching hospitals and whether the district was predominantly rural or urban. The selection also avoided any bias that might be attributable to the influence of regional offices by including MSLCs from different regions.

Intended sample

Using the above criteria, eight MSLCs were chosen for inclusion in the study. Substitutes were also identified in the event that any of the eight did not agree to be involved. The eight committees are shown in figure 5.2. Six were accountable to health

Figure 5.2: The intended sample



authorities and two were accountable to hospital trusts. Of the six accountable to health authorities, four covered just one main maternity unit and two covered more than one. Three were chaired by lay people, one was chaired by a consultant obstetrician, one was chaired by a health authority person, and the sixth was chaired jointly by a consultant and a lay person. One of the two MSLCs that were lay chaired and covered one unit did not have a remit with regard to clinical guidelines or audit (according to the NHS Executive survey). The two MSLCs accountable to hospital trusts were both chaired by lay people.

The sampling of interview respondents

The plan was to interview a cross section of members from each committee. The primary aim of the interviews was to find out how members experienced the MSLC and what they felt about the effectiveness and value of the committee. Interviews were to be conducted after one or two meetings had been observed, by which time the author would have gained an appreciation of the committee's work and how members interacted. The initial plan had been to interview the chairperson of each committee and one user member, one health care professional and one health authority representative. However, it became clear while observing the first few meetings that this would be insufficient to capture the full range of views. Each constituent group was made up of many subgroupings. For example, health care professionals included midwifery, medical staff and health visitors as well as GPs. Some midwives worked in the community, some in acute units, and others worked in both. Representatives from the health authority included public health doctors, commissioning managers and non-executive directors. User representatives came from the National Childbirth Trust, Community Health Councils, other user groups, or were there as recent users of the

service and not affiliated to any organisation. It might be expected that members from these various subgroupings would have different views on their MSLCs.

Given the practical limitations, it was not possible to interview someone from each of these subgroupings for each MSLC. The decision was therefore made to sample only from groups which were of the central importance to the work of MSLCs and were present on most committees. Based on this criterion, social workers and business managers were not interviewed. The second criterion was that those members who were actually most engaged with the work of their MSLCs should be interviewed. It was anticipated that these people would have the most informed views about the MSLC, its work and achievements and shortcomings. This degree of flexibility seemed appropriate in order to be able to follow up factors which appeared to be important to each individual committee. The task when choosing respondents was to ensure people from each of the main constituent groups were included as well as the most engaged members of each committee. The grounded theory principle of theoretical sampling (Pigeon 1996) guided the choice as to how many people were interviewed from each MSLC and each constituent group. Analysis of early observation and interview data informed the sampling of further interview respondents.

The application of these criteria resulted in a common core of interviewees from each MSLC, but variation beyond this in the number and type of member interviewed. The heads of midwifery from all the committees were interviewed as early observations showed that they were very active on their committees and were the major link between the MSLC and unit staff. GPs were considered to be of central importance to the work of MSLCs and the sample included those who were most engaged with their committees. A health visitor from one MSLC was interviewed because she was a central figure on the MSLC. At least one user respondent was chosen from each

subgroup. In two cases, the CHC representative was also the chairperson. Some MSLC members approached the author to say they would be happy to be interviewed before the author had started approaching members in this respect. The author decided to interview such people on the grounds that these people obviously had views they wanted to share and were well engaged with the work of their MSLCs.

Observation of the study MSLCs

The eight MSLCs were enrolled into the study between September 1996 and January 1997. The author contacted the person mentioned as the point of contact on the questionnaires returned in the NHS Executive's 1996 survey. In some cases this was the chairperson, in others it was the administrator or health authority person with responsibility for the MSLC. Where possible the author made contact with the person on the telephone to establish whether there was any interest in the study. In most cases a letter was then written to the chairperson describing the study and what would be required of the MSLC and its members. The project outline that was sent with the letter emphasised that the study was interested in the views of all constituent groups and that the anonymity of MSLCs and interview respondents would be protected. In most MSLCs the request was taken by the chairperson or other contact to the next MSLC meeting. All eight MSLCs agreed to be included in the study and observation of their meetings commenced between November 1996 and March 1997. At the first meeting the author introduced herself and the project.

An unstructured approach was used as little was known about the work of MSLCs and the process of communication between user members and health professionals. The plan was to observe all the main meetings of the eight committees over a one year period. A one year period was chosen so that the study could establish the way topics

progressed over time and the way MSLC work tied in with annual commissioning and monitoring activities. The author was placed on the circulation list for committee documents.

There are some limitations to what was observed. Only main MSLC meetings were observed - the author did not attend meetings of user subgroups and project groups. While such meetings might be interesting it was not thought that they would add much to the analysis, and limitations of time and budget rendered it unfeasible to attend in most cases anyway. It was recognised that the author would not be privy to informal exchanges about MSLC business that took place between people outside of meetings. However, in practice the author was included in some of these discussions during car rides and in car parks after meetings.

What was said and what happened at meetings was recorded as comprehensively as possible using Teeline shorthand. The notes were written up as soon as possible after the meetings. In total, 39 meetings were attended - between four and six in each MSLC. Two of the MSLCs that reportedly met four times a year, in practice met five times. The author missed one meeting in each of three MSLCs because of illness or because they took place at the same time as other MSLC meetings.

Advice to researchers in the literature explains that leaving the field can be problematic because of breaking attachments and leaving people feeling betrayed and used (Taylor and Bogdan 1984). Care was taken to maintain contact with MSLCs - usually through the chairperson - so that they could be kept informed of the progress of the study. A report was prepared for the committees within eight months of the end of the observation period and telephone contact was maintained with two chairpersons for over a year. The author did find it difficult to 'leave' the committees in that some people

seemed to value having someone to share their thoughts and frustrations with and were sorry the observation period had ended.

The interviews

The interviews were based around several topic areas and these are shown in box 5.3. The full interview guide with prompts is shown in the appendix. The intention was to pilot the guide with members of non-study MSLCs but time became so limited that it was decided to use the first two interviews as pilots. In the event they were included in the analysis as it seemed artificial to exclude them. The interview guide was refined over the course of the interviews as new questions and prompts were found to be useful.

The guide was composed of several different types of questions. Some sought factual information or accounts of what happened on the MSLC; others asked about the respondent's experiences of being a member. Some questions, such as those about achievements or the overall worth of the MSLC, required a degree of reflection and judgement on the part of the respondent. It was expected that respondents might need extra time to articulate their views where a question required a degree of reflection and judgement. Where it might help to clarify what they were saying, the author reflected back to the respondent what they seemed to be saying to check that she had an accurate understanding of their thinking.

Box 5.3: Interview topics and areas to cover

INTERVIEW TOPICS	MAIN AREAS TO COVER
Background	How and when became involved with MSLC; Involvement with other initiatives in maternity services
Experience of MSLC	Description of what the MSLC is like; what it is like to be a member
The purpose of the MSLC	What is the MSLC for?
The work of the MSLC	What are the important topics; who is involved; progress with the topics; influences on progress
Impact and evaluation of the MSLC	Perceived achievements and shortcomings; assessment of overall worth
Influences on the MSLC	What works well; what does not work well about the MSLC; what might improve the MSLC

The guide was developed so that topic areas would flow naturally, although it was permissible to cover the topics in any order. The same guide was to be used with all respondents, but there was flexibility to probe in greater depth in any area which seemed to be of importance to the respondent or which appeared to be so from observation. There was a certain amount of flexibility in the way interviews were conducted and the way questions were framed in order to accommodate the different backgrounds and experiences of members and to test out early findings. A degree of imaginative prompting was needed where respondents were not forthcoming or found it difficult to articulate their views.

Interviews took place between February and October 1997. Respondents were approached before or after MSLC meetings to request an interview. If this contact

proved hard to make, a letter was written describing the project and requesting a meeting. It was explained to respondents that the interviews were confidential and that care would be taken to ensure individuals could not be identified in any reports or papers. The interviews were conducted in whatever location was convenient for the interviewee. Interviews with health professionals were conducted in their offices and those with user members usually took place in their homes. The interviews took between 35 and 55 minutes and were recorded on audiotape. They were subsequently transcribed by the author

Data analysis

The interview transcripts and observation notes were analysed by a combination of manual and computer methods. The computer software used was NUDIST, a computer package for organising qualitative data. It is useful for code-and-retrieval and theory building. Combining analysis by hand and computer enabled the author to capitalise on the respective strengths and weaknesses of these two approaches. The computer package was useful in facilitating the analysis because of the large amount of data collected. The programme was particularly useful for coding small segments of text relevant to straightforward topics or ideas and for verification of findings. Working with paper copies of the interview transcripts and observation notes was helpful for obtaining and maintaining overall impressions of interviews or meetings and for analysing more subtle themes that did not manifest in single sections of text. Having hard copies prompted memories of the meetings and helped the author to form links across interviews and MSLCs.

The approach to analysis depended on the task. With regard to identifying the views of members on particular facets of their MSLCs, the text of the interview transcripts and

observation notes was coded to correspond with the area of inquiry. The interview guide provided several areas of inquiry. For example, the transcripts were searched and coded on the computer for comments relating to the achievements of the committee. These comments were found in response to direct questioning about achievements, but also elsewhere in interview and meeting transcripts and the author's notes. The analysis did not just focus on the nature of the achievement, but also on the way people talked about achievements. For example, it became clear that people had problems with using the term achievement in relation to the MSLC and preferred to talk in terms of benefits. Files containing the perceived achievements of each subgroup (users, health care professionals and health authority managers) were then printed out and categories of achievements were built up by identifying common themes and developing categories in an iterative way until the categories best fitted the data. Once the categories had been developed the notes were searched for differences and similarities across the subgroups.

Excerpts of transcripts were automatically labelled by the computer with a code assigned by the author. The code identified whether the person was a user, health care professionals or health authority manager, what their background was within this grouping, and then gave their initials. For example, a user member from the NCT with initials RS was identified by the code U-NCT.RS.

Organising observation notes to establish the progress made by the MSLCs in relation to their topics and how members contributed to this activity was carried out mainly by computer using word processing software. Text relevant to each topic of a MSLC was brought together in the relevant order using the cut and paste functions. Some topics were only a few lines long (and might be restricted to only one meeting) whereas others were pages long and text had to be collected from several transcripts.

Background information on MSLC topics and information as to what was happening behind the scenes was also retrieved from interview transcripts. From the information collated it was possible to identify the purpose, process and outputs of each topic. Brief summaries of the work and outputs of each topic were written (and formed the basis of the examples provided in chapter six).

A significant part of the analysis was to establish the various ways in which MSLCs acted upon their topics. (This knowledge informed the analysis of the roles played by MSLC described in chapter ten.) This was a complex task and difficult to accomplish by computer. The question used to guide the analysis was: 'What is the way the MSLC acted in relation to the topic?' The process was carried out by hand using cut-out summaries of each topic. These pieces of paper were sorted into piles according to the action that was identified and re-sorted over time as categories were refined. Eventually this process led to the development of five categories which accounted for nearly all the topics. It became clear that a small number of topics could not be classified because the information was insufficient or confusing and these were left out. The five types of activity are reported in chapter seven and include 'receiving and discussing reports about health care' and 'assessment of an aspect of care'.

The next significant task was to establish how members participated in the five types of activity. Tables were drawn up using word processing software with columns to describe the contributions to each topic made by users, health care professionals and health authority members. The task was based on answering the question: 'What did the members do?' On completion of the tables the author was able to identify themes in the way the different members participated. Differences and similarities between groups of members were identified. For example, users sought information on policy and practice and raised problems and health authority managers provided information

about public health issues and led or co-ordinated MSLC project work. The ways members contributed in relation to each type of MSLC activity is described in chapter eight. Analysis of the ways in which different members contributed to planning and monitoring activities and the running and development of the MSLC was conducted in a similar way.

The nature of the interaction that took place between members was then investigated. The aim was to examine features of the way people communicated, including the tone and the feelings that seemed to be manifested. This involved searching systematically through the transcripts of meetings looking at the interaction between different groups, for example, between users and health care professionals or users and health authority members. The interaction between members with the same background was also investigated. For example, with regard to health care professionals, this entailed the examination of interaction between midwives and health visitors. The author had made separate notes to record her impressions of the behaviour and emotions of members and these were a useful source of information.

The author read through hard copies of these notes and transcripts and for each type of interaction considered what the tone and approach of members had been. These findings were recorded along with a record of which MSLC and which meeting was involved. In this way it was possible to develop an appreciation of the feelings expressed and the dynamics behind the interaction. For example it was possible to identify the extent of frustration and antagonism that was present in relationships between some users and health care professionals. NUDIST was then used to code chunks of dialogue which were good examples of what was found. The findings are reported in chapter eight.

A substantial component of the analysis involved systematically searching through the interview transcripts, observation notes and files and documents generated in previous analyses for clues as to the factors that influenced how the MSLC worked and how users were involved. A list of influences was developed and overall themes identified. For example, in the list there were many instances where the health authority managers steered the decision-making in relation to topics in health authority-based MSLCs either directly through taking control or indirectly through such means as providing guidance to the chairperson. These types of comments seemed to fit well under an umbrella theme of how ownership of the committee influenced the remit of the committee and the extent to which users were involved.

In all parts of the analysis, establishing descriptive or explanative categories was an iterative process, where the categories were changed and refined over time to best fit the data. The analysis aimed to describe, to evaluate, and to explain at different points. It described what the MSLCs did and how members interacted, explained why MSLCs had developed in this way and what factors influenced this; and established how respondents evaluated their MSLCs and experienced meetings.

With any qualitative research there is a danger of the researcher overly-focusing on high impact findings or selecting only those observations that fits his or her preconceived ideas. Silverman (1985) argues that simple counting can play a part in ensuring the robustness of findings, since it gives the researcher a means of revising and testing generalisations. In line with this advice, the author took care to avoid biases by checking the frequency of observations and findings in the data. This was fairly easy to do in most parts of the analysis because systematic notes were made or generated through NUDIST or word-processing software. Concern with frequency in this manner does not mean that themes which occurred infrequently were disregarded

- this was certainly not the case, but the technique was helpful in keeping the author in touch with the data and promoted confidence that the findings accurately reflected the data.

In qualitative analysis there are many pitfalls to avoid: that of holistic fallacy, where events are interpreted as more patterned than they really are; elite bias, where the researcher over weights data from articulate, well-informed, high status informants; and going native, where the researcher loses a sense of balance and becomes co-opted into the perspective of certain stakeholders (Miles and Huberman 1994). In her analysis, the author used a variety of techniques to avoid these biases: checking outliers, looking for rival explanations for findings and looking for negative evidence. The computer package was a useful tool in this activity. The longitudinal nature of the study helped in avoiding some biases, by providing many opportunities to test out the relevance of findings at different times and in different settings. Elite bias was less of a danger in this study because all participants were articulate and the author is accustomed to working with senior health professionals. Going native could have been a very real problem in this study in that the author might have felt sympathy with the views of a particular subgroup. However, in practice the author found herself empathising with respondents from all backgrounds.

Ensuring the rigour of the study

This section looks at ways in which the rigour of qualitative studies can be ensured and how these approaches have been relevant to this study.

Up until the 1970s validity in qualitative research was discussed in relatively conventional terms, using the same definitions of validity that were applied in

quantitative research. Since this time there has been a great deal of debate about the appropriateness of using the same criteria and what - if any - terms would be more appropriate. Four basic positions in this debate can be identified. First there are those writers who argue that the search for any such criteria is fundamentally misconceived (Smith 1984). The defining characteristic of this postmodern position is a commitment to relativism or anti-realism. Proponents of this position argue against the existence of a context-free reality that endures across time and setting and therefore consider it misguided to try to apply a standard set of criteria across these different settings (Murphy et al 1999). The second position, which can be seen to lie at the other extreme of the debate, argues that there is no distinctive philosophy underlying qualitative research and that some version of validity and reliability should be applied to both quantitative and qualitative research (LeCompte and Preissle 1993).

Between these two views is a third position - sometimes called postpositivism - where researchers support some form of modified realism. This approach recognises the multiple realities that need to be taken into account but considers that there are characteristics of effective research inquiry which can be seen as relevant across different contexts. Proponents of this position talk about establishing the *trustworthiness* of the research and consider it appropriate to replace validity and reliability with concepts which are more suitable to qualitative research. There are different schools of thought on what these criteria should be. Some writers have sought to replace the four criteria characteristic of the quantitative paradigm - internal and external validity, reliability and generalisability - with more appropriate terms. Lincoln and Guba (1985) have developed four criteria by which to judge qualitative research: credibility, transferability, dependability and confirmability. These have been subject to a great deal of discussion and debate in the literature and have been further developed by other writers (Sandelowski 1986, 1993; Beck 1993). Credibility replaces

traditional notions of validity and involves demonstrating an appreciation of naturalistic inquiry and qualitative methods, researcher credibility and the use of rigorous techniques for gathering and analysing data. The criterion of transferability replaces generalisability. This posits that the researcher is able to develop hypotheses about the relevance of study findings to new settings given the in depth understanding he or she has gained of components of the study context and how these relate to the new setting. This contrasts with generalisability in quantitative research which is about identifying the phenomenon that exists across settings when factors to do with the context have been controlled for. Dependability replaces notions of reliability. Traditional approaches to assessing reliability assume an unchanging reality whereas the criterion of dependability appreciates that the entity being studied is likely to change and that this is not error of consistency which needs to be controlled. Confirmability replaces the traditional criterion of neutrality or objectivity with the idea that research cannot be value free and that participating in a study and interacting with a researcher will have an impact on how participants think, talk and behave. Rather than pursuing some notion of objectivity, it is important for researchers to provide an audit trail which allows others to examine the process by which researchers have arrived at their conclusions.

Other writers have emphasised criteria which have no direct comparison with criteria in the quantitative field, for example, there are those who argue that research findings should be judged in terms of their capacity for producing change (Owens 1982).

The fourth position, sometimes termed poststructuralism, contends that an entirely new set of criteria is needed which is not based on the quantitative paradigm or an adapted form of this (Richardson 1991). As one moves from the postpositivist to postmodern and poststructuralist positions, increased importance is attached to criteria such as

emotionality, subjective understanding and the nature of the relationship with those studied (Denzin and Lincoln 1994, p480).

It can be argued that the diversity of view that characterises the debate may in part reflect the divergent research methods that fall within the realm of qualitative research and the varying extent to which these approaches are similar or different to quantitative research (Murphy et al 1999; Sandelowski 1986). Methods such as grounded theory, ethnography and philosophical inquiry all have different rules concerning aims, evidence and inference (Sandelowski 1986). Therefore, it might be surprising if the same approach to promoting trustworthiness was relevant to all types of qualitative inquiry.

The study

The approach in this study drew on many of the assumptions behind the four criteria developed by Lincoln and Guba (1985). To promote credibility the author has sought to describe and justify the approach taken (see beginning of chapter), to be critical in relation to the sample of MSLCs and interview respondents, to be aware of the difficulties of accessing people's real views, to be rigorous and systematic in data collection and analysis, and to obtain feedback from respondents (see previous section for a description of data analysis in this study).

With regard to transferability, the author has sought to provide sufficient description of the settings and the findings to enable the reader to follow the arguments with regard to the potential relevance of the findings to new settings. In relation to dependability, the author has accepted that members' judgements on their MSLCs would be likely to change over time and that this might well be influenced by the observing and

interviewing process, particularly if this leads people to formulate and articulate views in a way which they would not otherwise have done. However, some effort was made to avoid interviewing people immediately after a committee meeting because they might be overly preoccupied with the content of that particular meeting. In practice this was not always possible but it was not found to be a problem. In fact, interviewing members straight after meetings showed the author the extent of the frustration and anger that some members went away with.

In relation to confirmability - which is based on the notion that subjectivity in research is unavoidable - the author sought to be aware of potential influences and make efforts to avoid partiality at all stages of the study (Guba 1978).

Issues considered by the author and approaches taken to promote the trustworthiness of this study are now considered in more depth.

Accessing respondents' honest views

There is always the question of how open and truthful respondents are during interviews. There was concern that, despite assurances of confidentiality, respondents might be inhibited from expressing strong or controversial views by the knowledge that the author was also talking to other members of their committee and reporting back at the end of the study. The frankness of many respondents provided some indication that this was not a significant problem for most people. It was quite surprising how open some respondents were about the problems of their committees. However, a small number of people did avoid mentioning the names of other members they were critical of and were circumspect about making harsh judgements about the overall value of the MSLC. They searched for less negative ways of describing shortcomings.

Rather than being an attempt to hide the extent of their negativity from the author, this seemed to reflect the fact that they did not want to be too pessimistic about the future even though they knew there were substantial problems. Only with one respondent did the author have a sense that the positive views they expressed in the interview were so at odds with their behaviour on the MSLC that it begged the question of how open they were being about their frustrations with the MSLC.

Promoting comprehensiveness

Triangulation involves collecting data using two or more different methods or using data from two or more different sources. Traditionally, it has been promulgated as a way of improving the validity of qualitative research whereby the researcher looks for patterns of convergence in the data collected through different methods or from different sources to corroborate an overall interpretation. The use of it in this way is now quite controversial and it is more likely to be seen as a technique for promoting the comprehensiveness of a study (Mays and Pope 2000). It might be possible that weaknesses in one method could be compensated by strengths in another, but writers such as Silverman (1993) argue that data from different sources can only be used to identify the context-specific nature of different accounts and behaviour. As such, triangulation is not a test of validity but a way of promoting a more reflexive analysis of the data.

In line with this thinking, this study does not primarily use the two methods of interviewing and observation as a way of cross-checking findings, but to get at different kinds of data and obtain a more holistic understanding of the phenomenon under study. Interviews were used to some extent as an opportunity to check the details of MSLC topics and find out what had happened behind the scenes, but this was a

secondary function. In a similar vein, this study did not seek views from multiple respondents because this would provide a way of cross-checking what was said but because it was important to study the different perspectives of stakeholders. Previous studies of MSLCs had sought only the views of user members and yet a knowledge of all perspectives is likely to be important to understanding the work and potential of MSLCs. The views that different types of MSLC members had of the achievements and worth of their committees would not be expected to correspond as members will interpret their MSLC's activity through the filter of their own values and expectations. Investigating how and to what extent members' views converged was an important part of the study.

Using respondent feedback

The view of Guba and Lincoln (1985, 1989) is that an important component of credibility is the extent to which the findings are seen by research participants to be a faithful rendition of their experiences. However, the extent to which credibility can be achieved through these means is the subject of some debate. There are many theoretical and ethical factors that need to be taken into consideration (Sandelowski 1993). Giving primary credence to the views of participants underplays the role researchers have in the research process. Researchers as well as research participants can be considered to be stakeholders in research and it might be expected that these two groups would have different aims and motivations. Researchers have found that respondents will inevitably look for themselves and their own reality in the findings and this does not necessarily fit with the researcher's aim of representing multiple realities (Sandelowski 1993; Bloor 1997). In addition, respondents might not be interested in providing feedback, or may not be honest for a variety of reasons, for example, their desire to be polite may override their motivation to provide critical

feedback (Sandelowski 1993). Given these factors, the view of many writers is that the primary purpose of obtaining respondent feedback should be to promote the comprehensiveness of the study rather than to obtain a benchmark for assessing the credibility of findings (Murphy et al 1998).

In this study, a report was prepared for the MSLCs which included a description of MSLC activities, an analysis of members' views on the achievements and shortcomings of their MSLCs, and conclusions as to the main challenges facing MSLCs. There was also a section describing the ways in which some MSLCs had tried to address some of their problems. The report contained a feedback sheet which stated that members could get in touch with the author directly or send their views via the chairperson. The intention was that the findings should reflect the concerns of all stakeholding groups but the author was also interested in whether the section describing the ways MSLCs had tried to improve might be of any use to them. Feedback was to be used as a way of promoting confidence in the findings by encouraging reappraisal where there appeared to be weaknesses in the author's interpretation.

There was feedback from nearly all chairpersons and one health authority representative, either by letter or telephone. The feedback indicated that the findings reflected their experiences and several chairpersons reported that they intended to work through the list of ideas provided in the report with their committees to see how they might be relevant. Some respondents were relieved to find out that their problems were shared by other committees. However, not everyone provided feedback and so it is not possible to say what views other participants held in relation to the findings. It is also possible that politeness and a wish not to offend the researcher may have

influenced the nature of the feedback that was provided, particularly given the friendly relationships that she had developed with some members.

Reflexivity and reducing bias

The quantitative approach requires the researcher to seek neutrality and distance in order to avoid contaminating the research setting and subsequently the findings. This is in contrast to the criterion of confirmability in qualitative research which assumes that research and researchers cannot be value-free, that scientific objectivity is itself an illusion, and that distance may not even be desirable as it is precisely the closeness of the researcher to the research setting which enables them to understand the phenomenon under study (Lincoln and Guba 1985; Sandelowski 1986). Within this school of thought, it is understood that studying something will undoubtedly change it in some way and that it is important for the researcher to be reflexive in relation to their own role in relation to the research findings and to consider how the study and their behaviour may be influencing the participants. In addition, it is desirable to have a rigourous approach to data collection and analysis to avoid bias in these areas as much as possible.

Understanding the influence of the observer on the observed

In this study, the author aimed to be as inconspicuous and non-threatening as possible. It was hoped that by observing over a period of one year people would have sufficient time to become familiar with having a 'stranger' in the room. However, in line with the school of though mentioned above, it was assumed that the presence of an observer and being interviewed would have some affect on MSLC members. By virtue of researching MSLCs and user involvement, the author could be said to be raising the profile of these locally and perhaps reinforcing the national importance of user

involvement. By interviewing MSLC members, the author required them to develop views and formulate judgements which they might not have done otherwise. That the author was not seen as a distant irrelevant figure was made clear by the hopes voiced by two chairpersons that having an observer might help to focus the committee on the work that it needed to get on with! It seemed that some people - in particular user members and those chairpersons who hoped the study might have a good effect on the committee - got a sense of encouragement from having an observer. They talked informally at length to the author about their committees and explained that it was good to have someone taking an interest.

In practice, the author's ability to fade into the background depended on the setting. She felt more conspicuous in smaller meetings where everyone seemed to know each other and most members took part in discussions. In these cases, it was more noticeable that there was a non-participating person in the room and, on occasion, member directed their comments at the author. In larger meetings, and those where several members did not participate, the author felt she more easily faded into the background. In that the author was white and middle class she was similar to nearly all members of the committees. The author asked a selection of interviewees how they had reacted to her presence at meetings. Some said they were aware of her presence at meetings but did not think it had had an impact on what happened on the MSLC. They explained that when there was a quiet moment or when there was some conflict on the committee they found themselves wondering what the observer might be thinking, but they did not think anyone was behaving differently. In addition, a small number of people (consultants and one GP) did not know there was an observer until they were approached for an interview, even though project proposals had been circulated and the author had been introduced at previous meetings where they were present.

In order to promote impartiality, the author aimed not to be associated with the perspective of any particular constituent group. The study's intention of seeing the work, achievements and problems of MSLCs from all perspectives was reaffirmed whenever the author was introduced at meetings or began an interview. In practice, members who were interviewed seemed to assume that she would be able to appreciate their point of view and did not appear to associate the author with the interests of any particular subgroup.

Promoting rigorous data collection and analysis

With regard to data collection, what was said at meetings was recorded as accurately and comprehensively as possible given the limitations of only recently acquired (and imperfect) shorthand skills. However, there were times when people spoke over each other or spoke so quickly that it was not possible to write down everything. Interviews were recorded on audio-tape to avoid any bias in recollection and were transcribed verbatim. In the interviews themselves, the author followed an interview guide. However, this does not rule out the possibility that the author had a tendency to focus on certain aspects of MSLC functioning or some question areas at the expense of others. The author conducted all the interviews and therefore there were no opportunities to compare interview techniques with fellow interviewees. Thus it is not known how different the interviews might have been if they had been conducted by another interviewer. The interview transcripts from the first five interviews were given to two colleagues to read and check against the interview guide (the project supervisor and a member of the advisory group). The emphasis on areas of inquiry did vary between interviews - as might be expected - but all areas of the guide had been covered.

The author also conducted all the study analysis. The risk of giving undue emphasis to some aspects of the data was reduced by having a systematic approach to analysis and regular discussions with two colleagues experienced in qualitative research. This was seen as a way of ensuring the comprehensiveness of the findings. It is accepted, for example, that a different researcher might have devised different terms for categories or concepts developed and that no one perspective is necessarily right or wrong. In line with the thinking of many qualitative researchers, the purpose of using multiple researchers to look at research findings was to furnish alternative interpretations, for them to act as 'devil's advocates' rather than to help the researcher identify some objective truth in line with thinking in the quantitative field (Barbour 2001; Popay et al 1998; Seale and Silverman 1997).

The eight study MSLCs

The structural characteristics of the eight MSLCs in the study are provided in table 5.4. They have been assigned a letter from A to H by which they are known throughout the thesis.

The sample of MSLCs that was finally enrolled in the study did not meet the sampling criteria in all respects. It became apparent at the first meetings of several MSLCs that they did not have all the characteristics that had secured their inclusion in the study. Those who were chosen because they had professional chairpersons were in the process of changing over to lay chairship. Soon after the observation period began, all but one of the MSLCs were being chaired by lay people. The decision was made not to seek replacement MSLCs which had maintained non-lay chairship because contact with several other committees outside the study provided some evidence that the changeover to lay chairship reflected a general trend for MSLCs.

Table 5.4: Structural features of the eight MSLCs

Accountable to:	Number of units	Chair-person	Size	Meetings per year	Location	Notes	Study code
the health authority	1 unit	lay chair	20	6	south-east near London		A
			19	4	north rural and urban	lay chairship began during observation	B
			12	4	north rural and urban	lay chairship began during observation	C
		consultant and lay	17	4	south-west rural and urban		D
	> 1 unit	lay	15	4	south-west rural and urban		E
hospital trust	1 unit	lay	14	6	south-east near London		F
			20	6	London urban		G
			11	6	south-east urban and rural	no remit in clinical guidelines/audit	H

One of the MSLCs that had been included because it reportedly covered more than one unit was found in practice to relate to only one. The result is that there is only one MSLC in the study that covers more than one main hospital maternity unit. And an MSLC which had been included because it was accountable to a health authority in practice had little contact with the health authority. It was therefore reclassified in the study as a committee accountable to a hospital trust (MSLC H). At this point all eight MSLCs had become engaged and interested in the project and it was not considered appropriate to withdraw any of them from the study.

Four of the study MSLCs are in the south-east (one in London, two near London, and one on the south coast), two are in the south-west, and two are in the north of England. The two in the north are in the same region. The eight MSLCs are in districts which vary in terms of their urban and rural mix. In the end no study MSLCs were included from the far north, Wales, Devon or Cornwall as it was considered too far to go for meetings given the budget and time available.

Interview respondents

All the 42 people who were approached agreed to be interviewed, although ultimately one interview with a GP (MSLC H) did not take place because it proved difficult to make an appointment and another with a chairperson (MSLC E) did not happen even though she was keen because of her personal problems. Table 5.5 shows who was interviewed and the distribution of respondents across the study MSLCs.

Box 5.5: The distribution of interview respondents across the study MSLCs

MSLC	Chair	Users			Health authority			Health care professionals					
								Acute			Community		
		NCT	CHC	other	PH	C	PA	PM	HM	CO	GP	HV	CM
A	ha nex	1			1	1		1	1	1			
B	ha nex	1					1		1		1		1
C	NCT			1	1				1	1			
D	CHC/ CO	1		1					1				
E				1 nc			1		1	1			
F	NCT		1 nc		1	1			1		1		
G	NCT								1	1 cp			
H	CHC	1							1			1	
T = 40	8	4	1	3	3	2	2	1	8	4	2	1	1

Key:

PH:	consultant in public health	HV:	Health visitor
C:	commissioning manager	CM:	Community midwife
PA:	nursing and professional adviser	PM:	Project midwife
HM:	Head of midwifery	ha nex:	health authority non-executive director
CO:	Consultant obstetrician	nc:	new chair during observation period
GP:	General practitioner	cp:	consultant paediatrician

In total, 40 people were interviewed: eight user members, seven health authority representatives, 13 hospital trust health care professionals, four community based health care professionals, and eight chairpersons. Chairpersons from seven MSLCs

were interviewed, including both the chairpersons of MSLC D. In two cases, user members who were interviewed took over the chair of their MSLCs soon after.

Some constituent subgroups were not covered as comprehensively as had been initially planned. Only two CHC representatives were interviewed and one of these was also the chairperson of the committee (although she had previously been the CHC user representative). The views of some midwives were not well represented because the decision was taken to interview all heads of midwifery and this left little time to interview other midwives.

Chapter six:

The structure of the study Maternity Services Liaison Committees

Introduction and summary

This chapter describes the membership, formal aims, accountability arrangements and committee procedures of the eight study MSLCs. During the observation period many of the MSLCs reviewed and made changes to aspects of their structure. The impetus for these reviews came from the recently launched NHS Executive guidelines (NHS Executive 1996). The reviews ranged from systematic assessment of the structure and functioning of the MSLC against suggestions made in the NHS guidelines, to unstructured and free-ranging discussions. Two MSLCs held special away days for their reviews. The reviews covered four main areas: the aims of the committee as specified in their Terms of Reference, their membership, committee procedures, and MSLC input to the planning and monitoring of maternity services. Changes made to the structure of MSLCs as a result of the reviews are described in this chapter; those made to the input they had to planning and monitoring processes in the health authority or trust are described in chapter seven.

The MSLCs varied substantially in size, but all had representation from local users, from providers of maternity and obstetric care and, in most cases, from health authorities. There was variation in the number and background of representatives from each constituent group. User members were from maternity user organisations, MSLC user subgroups, Community Health Councils or were not affiliated to any group. With the exception of most Community Health Council representatives, they were recent users of maternity services. The MSLCs had little representation from minority or

community groups. Most health care professional members held managerial responsibilities, although half the MSLCs also had representation from practising midwives and health visitors. By the end of the observation period, all the MSLCs were chaired by lay people. They had different backgrounds and experiences of maternity services.

The MSLCs met four or six times a year and most held their meetings at lunch times on hospital trust premises. Absenteeism and turnover of membership led to substantial variation in who was on the MSLC from one meeting to the next. Some meetings were without consultant or GP representation.

As stated in their formal aims and objectives, most of the MSLCs aimed to advise the health authority and/or hospital trust on the planning and monitoring of maternity services and provide feedback on services from local users. In the majority of MSLCs the MSLC role was advisory; only in the Terms of Reference of a few committees did the terminology indicate a more proactive role.

The MSLCs were accountable to a health authority or hospital trust. The main link between MSLCs and health authorities was through the health authority representative, and in some MSLCs the health authority representative was instrumental in guiding the work of the MSLC. The MSLCs that were accountable to hospital trusts had no links with the trust other than through the input of health care professional members.

* * * * *

Membership

Table 6.1 shows the membership of the study MSLCs. Membership was ascertained from observing who attended meetings, as the membership lists of many MSLCs were too vague or out of date to be useful. All eight MSLCs had representatives of local users, midwifery staff, hospital medical staff, general practitioners and health authorities, and all but one had health visitor representation. However, there was substantial variation in the number and type of members within each constituent group. Only a minority of the MSLCs had representation from trust management or social services.

There was substantial variation in the size of the committees. Average attendance at meetings ranged from six to 14 members. The largest MSLC had up to 19 members and the smallest had a maximum of seven during the observation period. The MSLCs accountable to hospital trusts (F, G and H) were smaller than most of those accountable to health authorities (A, B, C, D and E). The MSLC that covered the work of more than one unit (E) might have been expected to be the largest committee, but was in fact one of the smallest.

During the observation period, most of the MSLCs reviewed their membership and did so in line with suggestions in the NHS Executive guidelines. The recommended membership list contained in the guidelines is provided in Box 6.2. The composition of any individual MSLC was expected to vary according to the local population and the number, size and type of maternity units.

Table 6.1: Membership of the eight study MSLCs (numbers include deputies)

MSLC	A	B	C	D	E	F	G	H
Users								
NCT	2	1	1	1	2	1	1	1
CHC	2	1	2	1		2	2	2
other group				3		1	1	
non-affiliated	1				3		5	1
Total	5	2	3	5	5	4	9	4
Number at meetings*	2-3	1-2	2-3	2-5	1-4	2-3	3-4	1-3
Midwives / nurses								
head of midwifery	1	1	1	1	2	1	1	1
other midwives	3	3		2	2	3	3	1
community midwives	1	1			1			1
nursing		1		1		2		
midwifery education	1							
Total	6	6	1	4	5	6	4	3
Number at meetings	1-4	3-5	1	1-3	1-4	3-5	0-3	1-2
Medical staff								
obstetricians	3	2	1	3	2	1	2	1
paediatricians	1	2	1	7	1	2*	2	
anaesthetists	2	1		1		1	1	
Total	6	5	2	11	3	4	5	1
Number at meetings	2-3	1-3	0-1	3-7	0-1	0-2	1-3	0-1
Trust managers and non-executive directors								
business manager	2			2				
chief executive			1					
non-executive director	1			1				
Total	3		1	3				
Number at meetings	0-2		0-1	1-2				
General Practitioners								
GPs	2	2	3	2	1	1	1	1
Number at meetings	0-2	1-2	0-3	0-2	0-1	0-1	0-1	0-1
Health visitors / community service managers								
health visitors etc	2	2	2	3		1	2	2
Number at meetings	0-1	0-1	0-1	0-2		0-1	1	1
Health authority								
public health	1	1	1	2	1	1	1	
commissioning	2		1			1		3
Total	3	1	2	2	1	2	1	3
Number at meetings	1-3	1	1-2	1	0-1	0-2	0-1	0-1
Social services								
Social workers		2		1				
Number at meetings		0-1		0-1				
Total number of members at meetings	9-15	9-13	5-10	9-19	5-7	7-12	6-10	4-9
Average number of members at meetings	13	11	8	14	6	9	8	7

* shows the range in the number of members attending the MSLC's meetings. For example, there were two or three user representatives at the meetings of MSLC A.

Box 6.2: Membership suggested in the guidelines

CORE MEMBERS	ASSOCIATE / ADDITIONAL MEMBERS
Users * user members (nominated by voluntary maternity organisations, local women's or community groups and users' panels). * CHC member(s)	* users or community workers with particular expertise/experience eg. disability. * CHC officer
Health authority * public health representative * commissioning manager or other designated representative from list opposite	* consumer affairs / quality assurance manager * non-executive director * primary care development * health promotion
Provider unit(s) * consultant obstetrician * consultant paediatrician * midwife currently in clinical practice * senior midwifery manager * bi-lingual linkworker or advocate, where employed locally	other expertise as needed, for example: * anaesthetics * neonatal nursing * antenatal screening * non-executive director * bereavement officer * obstetric physiotherapy * business manager * parent education * chaplaincy * radiography * health promotion * infant nutrition * medical / midwifery education
Primary Care * general practitioner * health visitor	other expertise as needed
Local authority	* social services

User representatives

There were five main sources of user representation: local branches of the National Childbirth Trust (NCT), local Community Health Councils (CHC), national user organisations, local user groups, and recent users of maternity care who were not affiliated to any group. All the MSLCs had NCT members and seven had CHC representatives. In the MSLC without a representative from the CHC, the lay chairperson had originally fulfilled this function and continued to do so. Two MSLCs had representatives from nation-wide groups such as the Stillbirth and Neonatal Death

Society (SANDS); two had representatives from local users' groups; and half had at least one unaffiliated user member. In two MSLCs, unaffiliated users made up a large proportion of the user membership. The user membership of most MSLCs remained fairly stable during the observation period.

The guidelines suggested there should be members from local community and minority groups, but there were few such representatives. Some MSLCs made efforts to improve the representation of minority groups, but contacts proved hard to make. Promotional activities directed at service users had little success in attracting new members. The only success was in MSLC-C where user members recruited an Asian member who had contacts in the Asian community.

The guidelines suggest that user members should form at least one third of the total membership of an MSLC. Five of the MSLCs met this requirement, although not for all meetings. The MSLCs that were accountable to trusts had a greater proportion of user members than those accountable to health authorities. Three MSLCs (B, E and H) had a very low level of user involvement, with only one user member present at one or more of their meetings. Some of the MSLCs had plans to increase their user membership: two intended to invite women from their user subgroups to MSLC meetings, and a third planned to reduce the number of consultants in order to promote a better balance between user and health professional members. However, these measures had not been implemented by the end of the observation period.
There was evidence of resistance on the part of some health care professionals to increasing the user membership. They had concerns about how representative user members could be and one consultant went so far as to say that if new user members were recruited, he would feel unable to speak freely at meetings.

Trust representation

Midwifery and nursing staff

All the MSLCs had the hospital trust's head of midwifery as a member. All but one had additional midwifery members, most of whom had some managerial responsibility such as deputising for the head of midwifery or managing the labour ward. Half the MSLCs also had community midwives.

For most MSLCs, the main point of difference from the guidelines was the absence of practising midwives. Some had community midwives, but there were no (solely) practising hospital midwives. In addition, only a minority of MSLCs included the nursing or midwifery staff put forward in the guidelines as potential associate members.

The midwifery membership of two MSLCs underwent substantial change during the period of observation. MSLC-B started the year with six midwifery members and this was reduced to three following a review of membership. In the committee that covered more than one unit (MSLC-E), the membership was restructured so that the heads of midwifery rotated their membership and the trusts not represented by their head of midwifery would send a more junior midwifery manager.

Medical staff

Most MSLCs had two or three medical members, although MSLC-D had up to seven turning up at any one time. All eight MSLCs had representation from obstetrics, seven from paediatrics, and five from anaesthetics. Most representatives were of consultant status and held additional managerial responsibility or had special interests such as

fetal medicine. The MSLC with the largest number of medical staff planned to reduce their numbers on the grounds that it was intimidating for the users. Most of the doctors on this MSLC attended infrequently and barely participated in discussions. There were changes in the medical membership of three MSLCs during the observation period.

Trust managers and non-executive directors

Less than half the MSLCs had management or non-medical input from hospital trusts. Those that did were accountable to health authorities. Two MSLCs included obstetric department managers and non-executive directors and a third included the chief executive of the provider unit. The guidelines suggested that provider unit managers and non-executive directors should be associate rather than full members. In practice, the MSLCs did not appear to make a distinction. In fact, in one instance, the non-executive director of a trust was for a short time the vice-chairperson and then the acting chairperson of one MSLC.

Primary Care representatives

All the MSLCs had general practitioner representatives: half had one GP and the others had two or three. Those with more than one GP member had representatives from different geographical areas. One of the GP members had been on the advisory group that was set up by the *Changing Childbirth* Implementation Team to advise on the development of the NHS Executive guidelines. Seven out of the eight MSLCs had health visiting representation and four of these members held managerial responsibilities.

Health authority representatives

All the MSLCs had health authority representation: seven had public health consultants or nursing and professional advisers, and five had commissioning managers. The main divergence from the guidelines was that some did not have any commissioning representation. In addition, many did not have input from people suggested in the guidelines as potential associate members. Two MSLCs had input by health promotion officers, but only in relation to specific projects, and two had input from non-executive directors of health authorities, but the latter were involved as lay chairpersons rather than as representatives of their health authorities.

In two MSLCs there was a reduction in health authority membership during the period of observation. The health authority representative of MSLC-G left early on to take up membership of the newly developed district wide MSLC and the trust committee was no longer to have health authority representation. The public health consultant on MSLC-D left the health authority to take up another job and had not been replaced by the end of the observation period.

Two MSLCs had poor continuity of health authority membership. MSLC-H had a succession of three different commissioning managers during the observation period. The health authority representatives explained that the lack of consistent input was due to the restructuring of the health authority, but other members felt it reflected the health authority's lack of interest in maternity services or user involvement. The lack of interest in maternity services was attributed in part to the fact that all three representatives were men. MSLC-F was temporarily without a public health representative while she was on maternity leave.

Local authority representatives

The guidelines suggest social services representatives as associate members, but only two MSLCs had such input. Membership lists of some of the other MSLCs included social services representation but there were no such members in practice.

Chairpersons

At the end of the observation period, seven of the MSLCs were chaired by lay people and the eighth was chaired jointly by a lay person and a consultant obstetrician. Table 6.3 shows the chairpersons' backgrounds. Of the thirteen lay people who were chairpersons at some point during the observation period, nine were originally user members of their MSLCs, one was a senior health professional from the health authority, two were non-executive directors of the health authority and one was a trust non-executive director. All but one of the chairpersons who were previously user members had recently used maternity services, although they had not all used local services. The other chairpersons were men and women in their 50s and 60s.

Table 6.3: Background of chairpersons and changes during the observation period

BACKGROUND	A	B	C	D	E	F	G	H
NCT			2			1	1/2	2
CHC				1 joint	1			1
Unaffiliated user					2			
HA non-executive director	1	2						
HA Director of planning			1					
Trust non-executive director	2							
Consultant obstetrician		1		1 joint				

Key: HA: health authority; 1: chairperson at time observation started; 2: new chairperson.

The chairs of two MSLCs passed from health professionals to lay people during the observation period. One was initially held by a consultant obstetrician and the other by the health authority's director of planning. Some of the other MSLCs also changed their lay chairpersons during the observation period. There was no pattern to these changes.

The lay co-chair of MSLC-D had originally been the CHC representative on the committee. She explained at meetings that she was not to be seen as a lay chairperson from the CHC, but rather as a health authority appointment. In other MSLCs, the chairpersons did not distance themselves from the organisation they originally represented.

The guidelines state that the chairperson should be independent of those directly responsible for commissioning or providing services and should normally be a user member. By user member they were referring to recent users of maternity services. They stipulate that the chairperson should not be a non-executive director of a trust. One MSLC was chaired by a non-executive director of the local trust, however he soon asked to be replaced because of a conflict of interest. The guidelines explained that if there was no user member willing to take on the role of chair then the health authority, in conjunction with the MSLC, should consider who from outside the committee would have an independent perspective and be able to take on the role (NHS Executive 1996). The appointment of non-executive directors of health authorities in two MSLCs had been instigated by the health authority representatives and it did not appear in either case that a chairperson had first been sought from among the user members.

Attendance at meetings

Variation in the size of committees was in part attributable to differences in the number of members from each constituent group, but was also affected by absenteeism. Most MSLC meetings were attended by less than three quarters of their potential membership and three MSLCs had at least one meeting where less than half the membership turned up. A consequence of this absenteeism was that some MSLC meetings were conducted without representation of some constituent groups. Of the 39 meetings observed, all except one (97%) had user and midwifery representation, but less than three-quarters (74%) had health authority representation, only 62% had health visitor representation, only 60% in each case had obstetric or GP representation, and only 56% were attended by a paediatrician. The lack of representation was concentrated in specific MSLCs. Four committees (C, E, F and H) were often without obstetric or paediatric representation and four often did not have GP representation. Two MSLCs had no consultants or GPs at most of their meetings.

Nearly all meetings had user representation, but the attendance rates of user members in three MSLCs were poor. In MSLC-A, many of the user members missed two or more meetings whereas the majority of the consultants attended regularly. The attendance of midwives was good for all but one of the committees (MSLC-A). Many GPs were poor attenders, although three turned up to most meetings. Table I in appendix B shows the number and percentage of members in each constituent group who missed two or more meetings over the observation period. Reasons for absenteeism were only established in three cases. Two user members and a GP member were absent through serious accidents or illness.

Many MSLCs took on new members and lost others. Half the committees had substantial changes to their midwifery and medical staff and one of these MSLCs also took on many new user members. (See Table II in appendix B for comprehensive data on new and outgoing members.)

In order to maintain continuity of work, some MSLCs encouraged members to appoint deputies who could attend in their place, but this was difficult to achieve as it was not possible for everyone to identify a suitable substitute.

Structure of membership

The model terms of reference adopted by some MSLCs distinguished between full and associate membership. Core members had voting rights and were expected to attend every meeting. Associate members did not have voting rights and attended only for particular discussions. In practice, there was little difference in the way core and associate members were involved. There was no formal voting in most MSLCs and the distinction between members was not referred to.

Soon after the end of the observation year, MSLC-A introduced a two-tier structure of membership to improve the functioning of the group. A small core group of members was to meet regularly to carry forward the work of the MSLC and this would be joined at intervals by the remaining members.

Some MSLCs had a two-tier structure in that they had user subgroups that met separately and reported back their concerns to the main committee. In MSLC-D, the subgroup had been set up by the health authority and was not strictly a subgroup of

the MSLC, although in practice the MSLC was the vehicle by which its concerns were heard.

The appointment of members

The procedure for recruiting members such as users, GPs and health visitors was to request a nomination from the relevant organisation. In many cases, this procedure was no more than a formality as the MSLC had already identified an appropriate person. In the case of health professionals such as heads of midwifery and public health consultants, there was no choice about whom to appoint as it was the responsibilities associated with their posts that made them relevant to the MSLC.

During the year, some MSLCs reviewed the duration of membership. The guidelines suggest that members should normally be appointed for no less than two years and no more than four. In recognition of recruitment difficulties and out of a desire to maintain continuity, the MSLCs did not strictly enforce the maximum time limit of membership.

Aims and objectives

This section describes the formal aims and objectives of the MSLCs as stated in their terms of reference. Terms of reference were obtained from all but one of the study committees. None could be obtained from MSLC-F and members did not concur on whether or not any existed. The chairperson thought there were none; and those who thought they did exist were not forthcoming with a copy, nor could they remember the content.

Table 6.4 shows the aims and objectives of the MSLCs, as taken from their terms of reference. Three MSLCs adopted the model terms of reference provided in the NHS Executive guidelines, and their content is presented in the first column of the table. The columns to the right describe the aims and objectives of the other four MSLCs for which information was available.

To facilitate comparison between MSLCs, the aims and objectives of each committee have been reordered so that those most similar to the aims and objectives in column one appear in the same row. Any that do not correspond with the aims in column one are shown in the bottom row of the table.

Table 6.4: Aims and objectives of the MSLCs taken from their Terms of Reference

Model Terms of Reference Adopted by MSLCs B, D and E	MSLC-A	MSLC-C	MSLC-G	MSLC-H
Aims and objectives 1. The MSLC will advise the health authority and other commissioners on all aspects of maternity services provided for its residents, including:	To advise (the health authority, acute and community trusts) on all aspects of maternity care as appropriate.	To advise the health authority and GP commissioners on all aspects of maternity services for its residents.		To advise the purchasing authority and the provider unit(s) on maternity services, particularly on policy matters. ... by commenting on all proposals for development and change in the service, whether made by the purchasing authority or the provider unit(s)
(a) strategy for services		To revise the strategy for maternity services to address local need and incorporate the spirit of the Changing Childbirth initiative		To ensure that all mothers in the district have access to the best possible standard of maternity care to include choice, continuity of care and control by monitoring the implementation of the health authority's maternity strategy
(b) progress on the *Changing Childbirth* initiative in the district	To assist and advise on the delivery of the objectives of *"Changing Childbirth"*. Primary task: to assist and inform the development of a strategy to implement *"Changing Childbirth"*.			
(c) service specification for maternity service contracts	To advise (the health authority) on contracting for maternity services	To receive copies of service specifications relating to maternity service provision for information.		.. by commenting on service specifications on an annual basis
(d) quality standards for maternity services and ways of monitoring standards		To develop quality standards and monitoring mechanisms for maternity services		

MSLCs B, D and E	MSLC-A	MSLC-C	MSLC-G	MSLC-H
(e) guidelines for clinical care	To participate in developing and reviewing operational policies, protocols and guidelines for the provision of maternity care.	To receive copies of clinical guidelines relevant to maternity care for information	To ensure that the needs of women using maternity services are addressed in trust practice by providing consumer views on policies and guidelines prior to their introduction	
(f) the consistency in the delivery of maternity services and clinical practice across the district, based on reliable research evidence	To encourage clinical practice that is based upon reliable research evidence and adequate training and updating of staff.	To examine delivery of maternity services and clinical practice across the district against evidence of effectiveness - through receipt of audit reports and involvement of users		
2. The MSLC aims to ensure that the health authority and provider units take account of the views of women using the service	To seek the views of users, and potential users, of maternity services, and to feed these into decision-making processes	To ensure that the commissioners of maternity services and the provider units consider views of all women using the service	To ensure that the providers are kept up to date with the views and experiences of women using the maternity services	...by taking into account the views of the users of the service obtained both systematically and from the unsolicited comments and complaints of individuals. Anonymised complaints received directly or indirectly through a member should always be considered carefully
	To work towards ensuring that all mothers have access to the highest standard of maternity care within the resources available. To encourage good communication between different professional groups and between users and health professsionals, both in policy making and provision of care. To encourage the best use of professional skills and resources.	To liaise with the neighbouring MSLC within the same health authority on general issues affecting health authority residents To maintain awareness of the special needs of women as individuals. To propose ideas for research, surveys and audit of maternity services.	To inform the health authority of areas of concern to both providers and users within local maternity services, particularly where these have resource implications To produce an annual programme which focuses on specific areas with a view to monitoring and if necessary amending the policy of service delivery in these areas.	... by commenting on the provider business plan annually

Four of the five MSLCs accountable to health authorities adopted new terms of reference during the observation period as part of their general reviews of MSLC structure and functioning (see chapter seven). Three of these MSLCs adopted the model Terms of Reference without amendment and the fourth made some changes to wording. The fifth MSLC accountable to a health authority had aims and objectives from 1995 although they were very similar to those suggested in the guidelines. Of the two MSLCs accountable to hospital trusts, one had terms of reference from 1995 and the other produced new aims and objectives during the observation period. They were not based on the model provided by the NHS Executive guidelines.

All but one of the MSLCs had two sets of aims. The first set was concerned with advising the health authority and/or hospital trust in relation to the planning and monitoring of maternity services. The second set was about ensuring the health authority and/or trust takes account of the views of women who use the service, although only one MSLC specified how these views might be obtained. The aims and objectives of MSLC-G focused predominantly on the provision of users' views.

There was some variation in how proactive the MSLCs aimed to be in relation to planning and monitoring maternity services. The three MSLCs that adopted the model terms of reference aimed to *advise* the health authority and/or maternity unit and there was no elaboration of what this might involve. In other MSLCs, the wording indicated more proactive involvement, for example, MSLC-A was to *assist and inform* the development of a strategy and MSLC-C was to *revise* the strategy for maternity services (although this had not been done by the end of the observation period) and *develop* quality standards.

There was also some variation in how proactive the MSLCs were to be in relation to maternity and clinical guidelines. The MSLCs accountable to trusts indicated little or no involvement. Of the five MSLCs accountable to health authorities, one (MSLC-B) was to *receive guidelines for information* and three (C, D and E) were to provide *advice* to their health authorities and/or trusts in relation to the development and review of guidelines. The fifth (MSLC A) had a more proactive role and was to participate in the *development and review* of guidelines.

Accountability arrangements and financial support

Policy guidance relating to MSLCs indicated that they should be accountable to health authorities (House of Commons Health Committee 1992; NHS Executive 1996). However, the NHS Executive 1996 survey found that approximately one quarter considered themselves accountable to hospital trusts, so the study sample was selected to include MSLCs with both types of accountability arrangements.

The MSLCs that were accountable to health authorities had a variety of links with their health authorities. The links depended upon the behaviour of the health authority representatives. In two MSLCs (A and B), the health authority representative was the chairperson's right hand and instrumental in promoting links between the MSLC and the health authority. These were the MSLCs that were chaired by health authority non-executive directors. In three other MSLCs the health authority representatives were engaged with the work of the MSLC but provided less guidance in relation to planning and monitoring services or how links could be developed with the health authority. These MSLCs were chaired by user members. Only in one MSLC was there a direct link between the committee and the health authority board. This involved the lay

chairperson attending health authority meetings to receive direction and report on MSLC business.

MSLCs accountable to hospital trusts related to these trusts mainly through the head of midwifery. There was little contact between the MSLC and managers or the hospital trust board beyond the sending of annual reports, and even this did not appear to occur in all cases.

At the start of the observation period, none of the MSLCs had been allocated a budget and expenses had to be claimed in retrospect. The costs of photocopying and providing sandwiches at meetings were absorbed by the health authority or trust. Most chairpersons found arrangements unsatisfactory as they had to rely on the goodwill of health professionals and it was difficult to find the money to distribute published documents to MSLC members. By the end of the observation period, one of the MSLCs that was accountable to a trust had secured an annual budget of £1000 from the health authority. The health authority had not been keen to provide this but the MSLC had fought for it when it found out that other MSLCs under the same health authority had been given a budget.

Committee meetings and procedures

Location of the meetings

All but one of the MSLCs held their meetings on hospital premises. The exception, MSLC-E, covered more than one unit and held its meeting at the health authority. The guidelines suggest "neutral" ground should be found so that members can participate on equal terms, but also suggest that the location needs to be convenient to core

members (NHS Executive 1996). While hospital trust premises are not neutral, most people accepted the arrangement as it was convenient for healthcare members. However, some health authority representatives explained during study interviews that a negative consequence of having the meetings in the hospital trust was that the MSLC tended to focus solely on the work of that trust and did not consider all the other units that are used by the health authority's population.

Frequency of meetings

Five of the MSLCs had six meetings per year and three met four times per year. Maintaining the impetus of work was more difficult for those meeting four times a year, especially where attendance levels were low. If members missed one meeting, this would mean that they were out of touch with MSLC business for six months.

Timing of meetings

Six MSLCs held meetings at lunch times, one had meetings in the afternoon, and the other met in the evening at the beginning of the observation period but changed this to lunchtime soon after. The length of meetings ranged from one to three hours, with most lasting between 1.5 and 2 hours. In some cases, the meeting ran over the time allotted. The MSLCs that met four times per year had some of the longest meetings in order to get through packed agendas. Some members left early in order to meet other commitments.

Some MSLCs considered changing the day and timing of their meetings to make them more convenient. However, they could not identify a day or time that would be convenient for everyone. Lunchtime was considered the least problematic, but was still

difficult for some members. User members who worked had to rely on the flexibility of their working conditions; users who did not work had to find childcare; and consultants had to rush to or from clinics. Some MSLCs tightened up their start and finish times.

Structure of MSLC meetings

The agendas provided a structure for meetings. The agendas of some MSLCs were no more than lists of topics to be covered by designated people. Those of other MSLCs also had sections where users, health professionals and health authority managers reported anything they thought relevant or important. Where there were no opportunities for such reports, members used the any other business section at the end of the agenda. This arrangement did not always provide adequate opportunities for topics to be discussed because by the end of the meeting people were weary or had already left. On one MSLC there were standing slots on the agenda for hospital based health care professionals but none for other groups.

Administrative support

Most of the MSLCs accountable to health authorities were provided with administrative support by their health authorities, and the three MSLCs accountable to hospital trusts had secretarial support from their trusts. These staff took minutes and prepared agendas, but the administrators in the MSLCs accountable to health authorities also took responsibility for co-ordinating MSLC work. In the MSLCs that were accountable to hospital trusts, the lay chairpersons did much of the work co-ordinating MSLC activity. In the MSLC without any administrative support, the public health member produced the agenda, took the minutes and co-ordinated MSLC activity.

The guidelines state that the MSLC should have a designated secretary or committee officer to take minutes and work with the chair. The MSLCs without support or without someone to co-ordinate MSLC work wanted to increase their support, but in most cases health professionals explained that there was no one available to help.

Committee papers

In most cases, agendas for meetings were distributed well before meetings. However, due to poor management and the amount of work involved in producing papers, early circulation was not always achieved and this meant that important documents were tabled at meetings and members did not have the opportunity to read them prior to discussion of their content. The dissemination of published reports and documents was limited by the lack of resources to pay for them. Members were expected to get access to these documents through some other route.

On occasion, members were required to read and assimilate lengthy and complex documents. Some documents were not written specifically for a lay readership and contained health service language with which lay people and some healthcare professionals might not be familiar. The guidelines state that, where appropriate, papers should be available in other formats such as audio-tape. There was only one member who might have benefited from this - a partially sighted user member - but it was never discussed.

Some MSLCs reviewed the circulation lists for committee papers during the observation period and added new people as they were suggested. In this way they aimed to raise the profile of the MSLC's work and to ensure that people with overlapping work or interests were kept informed. Some of the MSLCs were quite open

with their documents and this was in line with the advice in the guidelines. The guidelines state that information on the clinical practice of departments or units should not be regarded as confidential. In practice, very little such information was contained in documents so there was no test of whether or not this would have been tolerated.

Expenses

User members and chairpersons were able to claim travel expenses but were not provided with childcare facilities or reimbursed for childcare costs. Most user members were out of pocket to some degree. Other members were not provided with expenses. The reimbursement of costs fell short of what was suggested in the guidelines (NHS Executive 1996). The guidance expected health authorities to cover costs of childcare and suggested that chairpersons and user members could be paid the standard public loss of earnings allowance.

Annual work programmes

The MSLCs endeavoured to become more proactive in their activities by developing yearly plans. Previously, MSLC priorities had been vaguely defined or not defined at all. Mechanisms for deciding these plans varied in formality and degree of democracy. In MSLC-E members voted on a list of potential topics to decide the next year's priorities. In other MSLCs there was an element of discussion and negotiation. In two MSLCs there was no discussion about MSLC priorities at meetings and they were established elsewhere by a core group of members.

Health authority and trust involvement in determining the priorities of the MSLCs was mostly through the input of their representatives on the committees. In some MSLCs

the health authority representatives were very involved; in others they took a back seat. The heads of midwifery in two MSLCs did not consider it appropriate they should be involved in deciding MSLC priorities - they thought these should be decided by user members.

Annual reports

All the MSLCs produced or planned to produce annual reports during the observation year. For some MSLCs, these were the first reports they had produced for many years. Reports were sent to the health authority and other interested individuals and organisations. They varied substantially in length and content. Some were very short and summarised the main areas of work of the committee; others contained substantial detail on developments in local maternity services which were not directly to do with the MSLC.

Annual reports were presented to the committee for members' feedback prior to circulation. Very few changes were made to reports at this stage. The experience of one MSLC demonstrated the potential problems that could arise from annual reports. A consultant obstetrician on MSLC-B was very angry about what she considered to be inaccurate and disparaging information on the quality of care in her unit. The report had already been circulated, so it was too late to make changes. The unit had provided the data she was referring to so any inaccuracies were not the fault of the MSLC. Nevertheless, the consultant directed her anger at the MSLC and in particular at the health authority representative who had compiled the report.

Summary of main points

The structure of MSLCs is likely to have a bearing on their effectiveness at improving maternity services as well as the extent to which users are able to participate. This chapter has shown up some potential limiting factors. The small number of user members on some committees, the high rates of absenteeism among consultants and GPs, the lack of resources, and the lack of involvement of some members in determining MSLC priorities, are all likely to affect what MSLCs can achieve and how well users can be involved. The impact of some other structural features of MSLCs is likely to be less straightforward. The MSLCs had a high complement of senior health care professionals and while on one hand this might promote the effectiveness of the committee, on the other hand it might intimidate user members. All the MSLCs had lay chairpersons, but they came from very different backgrounds and varied in the extent to which they identified with the interests of other user members. These issues are raised again in subsequent findings chapters. The impact of MSLC structure on the effectiveness of MSLCs and user involvement is discussed in chapters ten and eleven.

Chapter seven:

The work of the Maternity Services Liaison Committees

Introduction and summary

This chapter describes the work carried out by the MSLCs during the observation period. It looks at the topics they were involved with and the ways in which they contributed to them. It also assesses the extent of MSLC participation in the planning and monitoring processes of the health authority and hospital trust.

The MSLCs were engaged with a variety of specific aspects of maternity care. In relation to these topics they conducted assessment and project work, received and discussed reports on maternity services, raised and responded to problems with maternity services, clarified policy and practice, and were consulted for their input to new policies and practices. Some work had clear aims and discernible outputs such as changes to health care policies and recommendations for how services should be developed; but other activities did not have explicit aims, the work was unfocused and the outputs less tangible.

The MSLCs also had a limited role in relation to the systematic planning and monitoring of maternity strategy and health care policies and practices. Many tried to develop greater input during the period of observation and as a result increased the amount of information they received in relation to maternity strategy, service specifications, health care guidelines, clinical audit and complaints. However, in many cases it was not clear what the MSLC role would be in relation to the new information they received, or were planning to receive, nor what influence they were to have. In

general, health professionals were less interested than user members and chairpersons in increasing the MSLC's involvement with planning and monitoring activities, particularly those to do with health care practices.

* * * *

MSLC involvement in maternity services and health care

MSLCs were involved with a wide range of topics to do with midwifery and clinical care, including the content and implementation of healthcare policies and the adequacy of environmental conditions within maternity units. Their topics spanned all stages of pregnancy and childbirth, from antenatal care, through intrapartum care, to postnatal and neonatal care. They were also interested in service developments such as the implementation of team midwifery, and wider service planning in the district affecting maternity services. Some were also concerned with information given to local women about maternity services.

MSLC activity in relation to aspects of maternity care

The work conducted by the MSLCs over the observation period has been analysed to establish the variety of ways in which the MSLCs acted upon their topics. Five types of activity were identified and these are shown in Box 7.1. They are then described in more detail.

BOX 7.1: THE FIVE TYPES OF MSLC ACTIVITY IDENTIFIED IN THE STUDY
Assessment and project work
Reporting about and discussing maternity services
Raising and responding to problems with maternity services
Clarifying healthcare policy and practice
Consultation of MSLC members for their input to developments

Assessment and project work

The work that fell into this category involved assessment of a healthcare policy or practice, or was project work that led to a tangible product. Aspects of healthcare that were assessed included antenatal screening, information leaflets for women, and parent education. Much of the work was prompted by members' concerns about the adequacy of a policy or practice, or shortfalls in service provision. Other work was prompted by the launch of national initiatives, for example, user members of one MSLC were asked to review the recently published *Informed Choice* leaflets (MIDIRS 1996) - a series of leaflets describing choices available to pregnant women and the research evidence to support them. Project work included designing a leaflet on the choices available to pregnant women, and helping to run a publicity day to inform local women about maternity services and the work of the MSLC.

The depth of the assessment ranged from planned and systematic reviews of care to free-ranging discussions about a service and its problems. The more systematic assessments had clearly defined aims and processes, and discernible outputs. They provided systematic information on a service and made recommendations for how it could be improved. These were directed to the appropriate person on or outside the committee. For example, as a result of their review of antenatal screening, MSLC A

came to the conclusion that provision of routine Triple testing would improve the service and wrote to this effect to the health authority. Suggestions and recommendations, particularly those with funding implications, were not always accepted or acted upon and this was a source of frustration for MSLC members. The health authority of MSLC A did not agree to fund Triple testing.

Box 7.2: Examples of assessment and project work

A leaflet describing local maternity services (MSLC C) The user subgroup designed the leaflet and produced a blue print. The health authority representative was responsible for organising funding. Ultimately, the leaflet had to be cut in size because of costs.	**Assessment of postnatal psychiatric services** (MSLC D) The MSLC identified a problem with the referral process whereby access to the psychiatrist with the greatest experience of postnatal depression was solely determined by their geographical area. They planned to liaise with relevant agencies to try to change this.
Assessment of parent education (MSLC C) User members raised concerns about parent education; the head of midwifery presented her own evaluation; and the parentcraft co-ordinator presented her plans for the service. Members suggested improvements. It was not clear if any changes were made as a result; certainly there was no stated commitment to make changes.	**Review of antenatal screening** (MSLC E) A subgroup identified the screening programmes of the local units, compared these against the recommendations of research; and examined the rationale behind variations. They then categorised screening into that which should be routine, that for which different tests could be offered, and that which required further investigation.

Less structured work did not have explicit or clear aims and did not usually result in formalised recommendations or even a consensus view. The lack of focus reflected a lack of agreement among MSLC members about whether or not there was a problem with the service and a lack of commitment on the part of health care professionals to reviewing the service through the MSLC. Users raised their concerns, health care professionals described the service they provided and answered questions, and there was a substantial amount of discussion, but the intention of the MSLC was not formalised and the impact of this work was unclear.

Reporting work involved MSLC members informing their committees about healthcare policies and practices, service provision and organisation, or progress with wider service developments such as the relocation of maternity services to a new hospital site.

Box 7.3: Examples of reporting activity

Report on the implementation and evaluation of team midwifery (MSLC A) Provider staff reported on progress with team midwifery. A joint unit/health authority evaluation was presented and discussed. The MSLC planned to examine the implications of the evaluation's findings at a future meeting (after the observation period).	**Report of an audit of caesarean sections** (MSLC F) Midwives presented the findings of the unit's audit of the reasons for caesarean sections. Members discussed potential reasons for the high rate and midwives described the unit's plans to investigate and respond to the audit including the intention of clarifying the policy on management of breech presentation.
Report on implementing a new policy on medical checks for new borns (MSLC B) Health professionals reported progress developing and implementing new guidelines and new records. Led to discussion of the difficulties of resolving cross border problems.	**Report from a local breast feeding promotion group** (MSLC H) A user member who was also a member of the breast feeding group reported on the work of the group, including its survey looking at why women give up breast feeding, and its work to increase the availability of breast pumps.

Most reports were provided by health professionals and were verbal reports, although some were accompanied by written documentation. In some cases they were planned agenda items, sometimes they were given spontaneously during meetings as the topic arose, and in other instances were requested during the meeting. There was substantial variation between MSLCs as to the depth and breadth of reports on the same topics. For example, with regard to breast feeding support, some midwives provided in-depth reports about unit activities and talked about the problems they faced trying to increase breast feeding, yet others provided only brief information on the services they provided and were resistant to acknowledging any problems.

Reporting activity had the effect of keeping members informed about healthcare policies and practices, and progress with service developments. Health professionals explained the rationale behind service provision and acknowledged the problems they were experiencing. Members put forward their views on the quality of maternity services and got involved in debates about how things could be improved. In a small minority of cases, this process generated a solution. For example, the head of midwifery on one MSLC was having difficulty finding community bases from which her midwives could work and the community midwife suggested a potential site. Many reports were concerned predominantly with keeping the MSLC informed about progress with particular initiatives. The health professionals providing the reports did not necessarily seek to engage the MSLC in the problems and challenges associated with the topic.

Raising and responding to problems with maternity services

This category encompasses work where members raised problems with maternity services and other members responded to these problems. Most problems were raised spontaneously during MSLC meetings and consequently there was little or no warning of what would be raised. Most were about health care or environmental conditions within the local maternity unit. Problems to do with healthcare were to do with policy or practice, gaps in services, or shortfalls in service provision. Problems with the environment included poor security on wards and difficulties with access to wards and special care baby units. Three quarters of all problems were raised by user members and most of these were directed to midwifery representatives. The remaining problems were raised by GPs or health visitors and directed to various health care professionals.

Box 7.4: Examples of problems

Poor disability access in unit (MSLC C) User members raised concerns about the lack of provision for disabled women in the unit. There was discussion of what could be done and after many months the unit purchased a special cot for wheelchair bound mothers and arranged for the unit to be assessed by a local disability group	**Delays in postnatal baby checks** (MSLC G) User members explained that women were delayed from going home after the birth because of having to wait for doctors to turn up to conduct checks on their new born babies. Midwives and consultants blamed each other and this led to discussion of whether or not midwives should be trained up to perform the checks. (Midwives considered it a good idea; consultants thought it should remain a medical responsibility.)
Concern about inductions (MSLC F) A user member raised concern that inductions of labour were planned to fit in with organisational rather than clinical factors. A midwife explained that clinical factors are the main indication, but that organisational factors have some bearing.	**Shortfalls in access to scans at night** (MSLC H) A user member reported problems experienced by a local woman who was unable to obtain a scan at night at the local maternity unit. The head of midwifery explained the policy was to provide scans and that the problem was unusual and should not have happened.

The response of health professionals to problems raised by other members varied substantially. There was usually a degree of discussion in order to clarify the details of particular cases and to identify possible sources of the trouble. Health professionals put across their perspective in relation to the problem. On some occasions, explaining the policy was all that was required. For example, local women were concerned about inconsistent policies on administering Vitamin K to babies and the consultant explained that there were two policies and that both were good practice. In response to some problems, health professionals planned to pursue the matter outside the meeting. For example, a midwifery manager planned to investigate problems local women experienced navigating the various components of their first visit to the antenatal clinic. In response to some problems, the MSLCs wrote to relevant people to bring a problem to their attention and to express the MSLC's concern that it should be dealt with. For example, one MSLC wrote to the regional committee responsible for developing a district-wide policy on the administration of Vitamin K to babies to express its support for a particular policy.

On occasion, user members met with health care professionals outside MSLC meetings to further discuss a problem which had not been adequately dealt with due to lack of time or concerns about compromising the confidentiality of women and staff.

In most cases there was no feedback on what happened as a result of the MSLC's involvement. Sometimes users raised a problem again if their contact with local women showed it had not been resolved. This happened in relation to the above mentioned problems women experienced navigating an antental clinic.

In some cases, there was no agreement between members on the existence or the severity of the problem and therefore no consensus on what action should be taken. Health care professionals sometimes denied a problem existed or minimised its significance by describing the problem as highly unusual and unlikely to happen again. On occasion, they attributed a problem to a lack of resources or inadequate staffing, factors they considered beyond their control. These responses precluded a full investigation of problems and their implications.

Clarifying health care policy and practice

This category covers activity where members sought and received information about maternity services. This included information on healthcare policy or practice such as whether or not GPs could prescribe folic acid, the availability of services such as debriefing by midwives after difficult births, and what information is given to users, including that provided about the dangers of smoking in pregnancy.

Box 7.5: Examples of clarification activity

Cystic fibrosis screening (MSLC C) The public health representative explained that screening for cystic fibrosis was not funded by the health authority because of its high costs. Members debated the costs and benefits of this approach. Some thought the screening test should be available.	**Choices given to pregnant women** (MSLC F) Clarification was sought by user members on whether GPs gave pregnant women a choice of maternity unit. A GP explained that women did in theory have a choice, but she preferred her patients to use the local unit because this allowed for greater continuity of care during intrapartum and postnatal care.
The availability of Meptid as pain relief during labour (MSLC F) A user member asked if the pain relief drug Meptid was to be made available in the unit. Midwives acknowledged that it is preferable to Pethidine, but explained that it was not available because of its higher cost. The MSLC wrote to the relevant committee in the trust to express its support for the introduction of Meptid.	**How a piece of equipment on the labour ward works** (MSLC H) A user and a health visitor asked what the new Roman birth wheel was for and how it worked. The head of midwifery described it and suggested members see it on a forthcoming tour of the maternity unit (which they did).

User members made most of the requests for information, although some GPs asked for clarification of policies and practices. The need for clarification arose because members or their peers had experienced problems accessing services and they wanted to ascertain whether this reflected actual policy or was due to shortfalls in provision. In most instances, midwives and consultants were able to respond to the requests. In the few cases where the query could not be answered by a member of the MSLC the information was sought elsewhere.

Through receiving clarification members became better informed about policies and practices and the availability of services where previously there had been an element of doubt or confusion. In some cases, the rationale behind changes to services or policies was explained. For example, users were confused about whether or not a GP-based obstetric clinic actually took place and midwives explained that it had been stopped because demand was not great enough to justify the expense. Sometimes the information provided had an impact or potential impact on the behaviour of members, for example, a GP found out that she could refer her patients out of district for nuchal

screening and aimed to do so in the future. In other cases, the information might have an impact if it was passed on to local users. For example, if user members tell local women that in order to avoid being continually monitored during labour (continual monitoring limits movement) they will need to be proactive in asking for the monitor to be removed, this might make women more assertive.

Consultation of MSLC members for their input to developments

This category encompasses activity where MSLCs were asked for their views on a new policy or initiative. Most consultation was in relation to health care or service development, although some was in relation to information given to local women about particular services. Consultation was initiated by health professionals within or outside the MSLC, or requested by other members, usually users. Some MSLCs were trying to ensure they were properly consulted in the planning of new maternity units.

Box 7.6: Examples of consultation activity

Identifying children at risk (MSLC A) A community health services manager proposed that health care professionals use a screening questionnaire with pregnant women to identify babies at future risk. Health professionals were not supportive because of concerns about breaching the trust they have with their patients. They asked for information on the signs of abuse to look out for and information on services they can call on if they identify a problem	**Review of 'Informed Choice' leaflets** (MSLC D) The health authority representative asked the user subgroup to review the leaflets and indicated that their feedback would inform the health authority's decision about whether or not to buy the leaflets. User members found many problems with the leaflets and this led to a discussion about the potential for using the money to produce more relevant local information. The impact of the discussion was not clear.
Smoking cessation programme (MSLC A) A health promotion officer consulted the MSLC about a project proposal to stop pregnant women smoking. The proposal required doctors and midwives to be more active in encouraging women to stop smoking. Health professionals were not happy about the potential increase to their workload and suggested what was really needed was more community based support.	**Postnatal ward visiting** (MSLC E) A midwife described the unit's plan to promote privacy on postnatal wards by reducing the number of visitors per bed. Members agreed that privacy should be a priority but user members wanted the new policy to allow for some flexibility. Midwives reassured the MSLC that the policy would not be enforced too rigidly.

There was not always consensus among MSLC members and not everyone's views were taken on board. In some cases there was a degree of compromise. For example, health care professionals did not want women to eat or drink in labour because this increased the risk of choking under a general anaesthetic in the event of an emergency, but user members were keen that women should be allowed to eat and drink and believed this to be in line with the research evidence. After much discussion it was agreed that women should be allowed to eat and drink within negotiated parameters.

As a result of being consulted, MSLC members expressed their views on the quality of health care and the appropriateness of initiatives, and made suggestions for how they could be improved. On occasion, health professionals agreed to make changes to policies or practices. In theory it should be possible to assess whether MSLC input had actually been taken on board in policy documents. However, MSLCs did not always see the final document. Members of one MSLC made substantial changes to a new draft of the maternity unit's antenatal guidelines, but many months later they still had not received any feedback on how their comments had been incorporated. Where changes were not written down or formalised into a standard or policy it was even more difficult to establish the impact of the consultation activity. This was the case with the policy on eating and drinking in labour mentioned above and the policy on ward visiting described in Box 7.5.

Comparison with the NHS Executive guidelines

The guidelines suggest that MSLCs can take the principles outlined in *Changing Childbirth* to set local priorities and goals and then review progress made towards these. The main thrust of the *Changing Childbirth* initiative was to promote continuity of

care for women. Many MSLCs were involved with this in that they had reports and discussions about the development of team midwifery. It was not possible to assess the extent to which MSLCs had been involved in the early stages of planning team midwifery because the schemes started well before the present study began. Comments made by members indicated that the MSLCs had very little input, with the exception of MSLC-A which set up a task group to promote the implementation of team midwifery.

The guidelines provided specific advice for MSLCs in relation to only one other aspect of the *Changing Childbirth* initiative - that of information given to local users of maternity services. The MSLCs did not do a great deal of work in relation to information, with the exception of MSLC-C which produced a leaflet describing local services and two other MSLCs (G and H) which formed subgroups to review all the information given to women during antenatal care. In practice, the potential to improve information was limited by lack of funds and lack of commitment on the part of midwives.

Variation between MSLCs

There was some variation in the extent to which MSLCs carried out the five different types of activity. Most of the MSLCs conducted a substantial amount of assessment and reporting work, but not all did anything that could be classified as clarifying policy or practice, raising problems, or consultation. There was also variation in how much of the activity MSLCs carried out. For example, some MSLCs had very little activity that could be described as raising and responding to problems, whereas for two committees this constituted one of their main activities.

Table 7.7: The activity of the study MSLCs

TYPE OF ACTIVITY and Topics	A	B	C	D	E	F	G	H
Assessment and project activity								
antenatal screening	■		■		■			
information			■			■	■	■
charter for ethics in research				■	■	■		
other eg. Parent education			■	■	■		■	■
Reporting activity: Healthcare policies and practices								
antenatal screening		■	■	■		■		
breast feeding	■		■			■	■	■
babies' health	■	■		■	■			
parent education	■					■		
other eg. birth statistics	■	■		■		■	■	
Maternity service developments								
team midwifery	■	■	■					
unit facilities	■			■		■		■
staffing	■		■				■	
staff education	■					■		
other eg. birth plan developed	■			■	■	■	■	
Major service developments								
eg. Maternity unit moving	■	■		■				■
Raising and responding to problems								
healthcare	■	■				■	■	
lack of service	■			■		■	■	
gaps in service delivery	■						■	■
funding	■		■	■				
environment	■		■				■	
Clarifying policy and practice								
healthcare policy and practice	■					■		
provision of healthcare			■	■		■		
Information for women				■	■	■		
Consultation								
smoking cessation	■		■		■			
healthcare policy / practice	■				■		■	
planning new units	■			■				
information for women				■		■		
other				■				

Some aspects of maternity services, such as antenatal screening and breast feeding promotion were of interest to most or all MSLCs, although there was variation in what they did about these. MSLCs also had more idiosyncratic concerns, such as the accessibility of postnatal psychiatric support and the impending relocation of maternity services to a new hospital site.

Some topics were associated with particular types of activity. For example, antenatal screening and parent education were commonly the subjects of assessment work, and breast feeding and team midwifery were often the focus of reporting activity.

MSLC involvement with planning and monitoring processes

The MSLCs were interested in planning and/ or monitoring local maternity strategy, health care policies and practices, and users' views. Much of the work in relation to strategy and health care was started as a result of MSLC reviews of their own effectiveness and was heavily informed by the NHS Executive guidelines.

The planning and monitoring of maternity strategy

The guidelines suggest that MSLCs need to be involved in developing strategies for maternity services and should be consulted during the development and annual review of service specifications. If they are not involved in developing strategy then it is expected they should have close links with groups that do this. The input of many of the MSLCs fell short of these expectations, but some tried to change this. At the outset of the observation period, most MSLCs did not have a copy of their local maternity strategy document nor were they consulted on the development of service specifications. Three MSLCs discussed what role the MSLC should have in relation to the maternity strategy document. One decided that it would simply respond to the strategy when requested to do so by the health authority. The second found that the strategy document was out of date and debated whether or not the MSLC should take on the task of updating it. Members decided this was feasible if the document was kept brief and focused on assessing the trust's progress in meeting the requirements of *Changing Childbirth*. This report had not been written by the end of the observation

period. In the third MSLC, some members wanted to obtain the maternity strategy document and assess the service against this, but were put off by other members who explained the document was too out of date for this task to be meaningful.

In three MSLCs there was no discussion in relation to developing or reviewing maternity strategy because there were other groups which did this. The committees had links with these other groups: two were represented on district-wide committees which were concerned with maternity strategy and a third had overlapping membership with the district's maternity strategy group.

In some MSLCs it was decided that documents other than the maternity strategy were of greater relevance to the MSLC. In one MSLC, the health authority representative explained that the local development plans were more relevant to the MSLC than the maternity strategy document which covered the entire district. She was responsible for producing the relevant local plan and agreed to incorporate the MSLC's priorities. It was not clear how this would help the MSLC to achieve its aims. Two MSLCs discussed what they should do in relation to service specifications and contracts. One planned to develop a service specification for maternity services to form part of the contract between the hospital trust and health authority and the other planned to receive quality specifications twice a year. The latter had a presentation from the assistant director of purchasing about contracting and purchasing and this led to a discussion of how the MSLC could be involved. It was decided that the health authority representative would be the link between the MSLC and planning and monitoring processes in the health authority and that she would bring relevant documents to the committee.

Discussions were characterised by a degree of confusion as to what the various documents were and what an appropriate role for the MSLC could be. Members did not always agree that the MSLC should get involved. Some MSLCs discussed the strategy document and service specifications without actually seeing the documents.

Many MSLCs were engaged with the planning and monitoring of maternity strategy in the widest sense, in that they received reports and had discussions about team midwifery, continuity of care and other *Changing Childbirth* topics. Promoting team midwifery and continuity of care was the main long term strategy of most maternity units.

Planning and monitoring health care

The NHS Executive guidelines suggest that MSLCs can have a role in the review and development of guidelines and that they should be consulted about the programme for clinical audit and make proposals for audit topics. The MSLCs had little systematic involvement in these activities but some MSLCs attempted to change this.

Maternity and clinical guidelines

In most cases there was no established principle that the MSLC should be routinely consulted about the development and review of health care guidelines. Where they were engaged this was ad hoc in relation to specific guidelines and dependent on the agreement of health professionals.

Three MSLCs discussed what role they should have in relation to the development and review of health care guidelines. In general, user members were more keen than

health care professionals that the MSLC should have input. Some health care professionals considered it acceptable for the MSLC to have input to maternity guidelines for routine care, but not clinical guidelines as the latter are solely the responsibility of doctors. In two of the three MSLCs the heads of midwifery agreed the MSLC could have access to maternity guidelines relating to routine or normal care. In one case the MSLC was only to receive them when they were under review. Health care professionals were reluctant to involve the MSLC at the development stage because this would make the consultation process more lengthy and unwieldy. In the third MSLC, it was decided that the MSLC would receive guidelines only for information. At the end of the observation period it was too early to say what these new arrangements would amount to.

Clinical audit

The MSLCs had little involvement in clinical audit at the start of the study but there were a few changes to this position during the observation period. At the beginning of the study only MSLC-A had regular reports on the unit's audit programme and only MSLC-F received the results of an audit.

During the observation period, three MSLCs accountable to health authorities discussed how to increase their role in planning and monitoring clinical audit. In one MSLC (A) the public health representative organised a presentation by the health authority's audit analyst on audit structures in the district. User members asked how the MSLC could influence audit topics. It was clarified that it is up to the MSLC to be proactive in proposing topics. In the other two MSLCs it was decided they would receive regular reports on the unit's audit programme. Health professionals did not think user members appreciated the amount of work involved in putting the information

in a suitable format for the MSLC and were concerned that users expected more detail about unit audits than they would get from reports. A small number did not think it appropriate for MSLCs to have this information at all.

Monitoring users' views

The guidelines suggest that the MSLCs should find out the views of current and recent users, inform or oversee the monitoring activities of health authorities and hospital trusts, and use feedback from women, including complaints, to identify problems and monitor changes. They state that particular effort needs to be taken to seek the views of minority groups.

Some MSLCs tried to improve their monitoring of users' views by increasing user membership on the MSLC (described in chapter six). A small number of committees increased the number of users or had plans to do so. Other methods used by MSLCs to monitor users' views were user subgroups, conducting or collaborating in surveys of local users, forging links with minority groups, and receiving reports on formal complaints.

User subgroups

Two MSLCs already had user subgroups and two others developed user subgroups during the observation period. Despite putting up posters, MSLCs found it difficult to recruit women and some of the subgroups did not have the diversity of background that had been initially hoped for. In most cases it was not clear how the subgroup's work would link in with that of the MSLC and how its findings would be implemented. User members who co-ordinated the subgroups presented the findings of subgroup discussions to the MSLC but there was little response from health care professionals,

apart from them calling into question the representativeness of women in the subgroup.

Surveys of local users

Two MSLCs were involved with large scale surveys of local users. MSLC-H conducted its own survey of local women and convened a subgroup to promote implementation of the findings. The survey demonstrated several areas of concern to local women but, by the end of the observation period, little action had been taken to address them. There were no consultants present at most of the meetings of this MSLC so it was not possible to pursue the problems relating to clinical care. The second MSLC (A) collaborated with the health authority on its questionnaire survey. The survey had a very low response rate and focus groups were set up as an alternative way of obtaining users' views. Surveys and focus groups were criticised by some health care professionals for representing the views of only a narrow band of women. Very little action was planned to attend to the problems raised in the focus groups. User members of a third MSLC made regular visits to postnatal wards to talk to women about their experiences and fed back any problems to the MSLC. They saw this method as a less costly alternative to questionnaire surveys.

MSLCs did not have any involvement with user surveys conducted by maternity units except in one case where midwives reported the findings of the most recent survey. The head of midwifery of a different MSLC told the author in private that she might involve the MSLC in the unit's survey at some point in the future, 'when the time was right'.

Links with community groups and ethnic minorities

At the outset of the observation period, MSLCs had little or no contact with community and minority groups but three made new contacts during the study. User members of one MSLC were in contact with the local Asian community. The third MSLC made special efforts to distribute its survey questionnaires to as wide a range of women as possible, including single mothers, teenage mothers and women living in deprived areas.

Complaints

With regard to monitoring complaints, two MSLCs already received brief summaries of formal complaints and two decided to receive regular reports. The latter had received first reports from their heads of midwifery by the end of the observation period. There was little discussion of the complaints in any of the MSLCs and it was difficult to see how the information given could help MSLCs to monitor users' views.

Summary of main points

The MSLCs were concerned with a wide range of topics in maternity services. Some work had discernible outputs in terms of recommendations or changes to practices, but more often the contribution of the MSLC was not well circumscribed or formalised. In most cases, they were not systematically involved in the planning and monitoring processes of health authorities and trusts - MSLC input to maternity services was usually informal and ad hoc. They made some moves to formalise their input, but little had been achieved by the end of the observation period.

Chapter eight:

The participation and interaction of MSLC members

Introduction and summary

This chapter investigates the ways in which members participated in the MSLC and communicated with each other. Special attention is given to establishing the different input of users, health care professionals and health authority representatives. It looks at how the different members participated in healthcare topics, the planning and monitoring of maternity services, and activity to do with the running and development of the MSLC itself. The nature of the interaction between members is then described.

Users raised problems with services, sought information on policy and practice, contributed to the development of health care practices, and provided information on voluntary services and organisations. User members led or collaborated with others in the monitoring of users' views through such means as user subgroups. User chairpersons led reviews of MSLC structure and effectiveness, and produced Terms of Reference and annual reports. They instigated discussions about increasing the input of their MSLC to the planning and monitoring processes of the health authority and trust.

Health care professionals provided information about policy and practice, responded to problems raised and suggestions made by others, raised problems themselves, and made suggestions for how services could be improved. They explained clinical audit and how health care guidelines are developed and expressed their views on the

appropriateness of MSLC involvement. Some worked with user members in surveys and setting up user subgroups.

Health authority representatives provided information about health authority decisions and public health issues, responded to problems relating to the funding of maternity services and the health authority's referral policies, led or co-ordinated MSLC work, and consulted the MSLC for its views on health authority initiatives. They explained processes to do with planning and monitoring maternity strategy, provided documentation, and advised on how the MSLC should and could be involved in planning and monitoring activities. They led or facilitated reviews of the effectiveness of the MSLC and worked with the lay chairperson to produce Terms of Reference and annual reports.

Much of the interaction between users, health care professionals and health authority members was friendly and constructive. However, there were times when it was fraught with criticism, defensiveness and frustration. Health care professionals became defensive about problems raised by users and there were fundamental conflicts in their beliefs about maternity services. The interaction between health authority representatives, user members and health care professionals was generally neutral or good, but could deteriorate when frustrations about health authority decisions and resource problems surfaced.

* * * * *

Participation in MSLC work relating to healthcare topics

This section describes the contribution of user members, healthcare professionals and health authority members to the health care topics of MSLCs. The previous chapter identified five types of MSLC activity to do with health care: assessment and project work, reporting, dealing with problems, clarifying healthcare policies and practices, and consultation. Table 8.1 provides a summary of the ways members participated in these. In all the tables and text in this chapter, user chairpersons are included in the sections on user members.

Table 8.1: Participation of members in work relating to health care topics

TYPE OF ACTIVITY	USERS	HEALTH CARE PROFESSIONALS	HEALTH AUTHORITY PROFESSIONALS
Assessment/ project work	Promoted focus on context of care; instigated / conducted some work	Provided information on and explained policy and practice; responded to suggestions	Led or co-ordinated subgroups / project work; provided a link with the health authority; explained funding issues
Reporting and discussing maternity services	Requested reports; questioned health professionals on the content of reports; informed MSLC about voluntary services and consumer issues	Reported and explained policy, practice and other initiatives (midwifery managers and consultants)	Provided reports on referral policies and other work of the health authority; reported public health issues
Raising and responding to problems	Raised problems they or other women had experienced with maternity services	Responded to problems (midwifery managers and consultants); explained practices; planned to rectify / investigate problems; raised problems (GPs and health visitors)	Responded to problems to do with funding services and public health issues; explained health authority position
Clarifying policy and practice	Requested clarification of policies and practices or progress with initiatives	Explained policies and practices (midwifery managers and consultants); sought clarification of policy or practice (GPs)	Clarified health authority policies and funding decisions
Consultation of MSLC members	Sought MSLC / user input to the review and development of policies and practices; made suggestions for change	Consulted by visiting health professionals on plans for new initiatives; responded to MSLC views' on their policies and practices; sought the input of the MSLC	Sought MSLC or user views on potential new developments

Users, health care professionals and health authority professionals participated in all five types of activity. They were members of multidisciplinary subgroups set up for assessment and project work, they contributed to discussions with opinions and ideas. However, they participated in some fundamentally different ways.

User members

User members participated in health care topics in four main ways: by raising problems with services; by seeking information on policies, practices and initiatives; by contributing to assessment and project work, and the development of health care policies and practices; and by providing information.

Their main roles were raising problems and seeking information. They reported problems experienced by themselves or local women to health professionals at MSLC meetings. They also drew on their pool of knowledge about problems women experienced with local services in discussions associated with reporting activity and assessment and project work. They described problems to demonstrate weaknesses with services. They sought information on practices, policies and initiatives to pass on to local women or to promote their own understanding so they could contribute to discussions about how maternity services could be developed.

User members had input to the development of initiatives and health care practices through assessment and project work and by making suggestions for the development of health care policies. Their input was characterised by a focus on contextual aspects of health care such as the way doctors and midwives communicate with their patients. Their input was not usually formalised nor systematic. They tried to 'negotiate' with health professionals, stating their views and making suggestions for how things could

be changed. Some projects were led or conducted by user members, including those trying to improve the information given to local women about maternity services.

User members provided information to the MSLC about voluntary services and organisations so that health professionals would be aware of what was available for the women they had contact with. They also reported on progress with joint initiatives between user members and health care professionals.

There was variation in how proactive user members were. Some user members instigated a great deal of the work of their MSLCs, by raising problems, asking for information and requesting input to the development of health care policies. The ways in which user members participated was to some degree dependent upon their interests and the extent of the contact they had with local women. Users who provided antenatal classes and breast feeding counselling had greater access to problems experienced by local women than did some CHC or unaffiliated members. They were aware of what information users wanted and what of the information that was available was not reaching them.

Health care professionals

Health care professionals participated in several ways: by providing information, responding to problems raised by other members, seeking and responding to the input of others to policy and practice, and having input themselves to service developments. Some health care professionals, notably GPs, community midwives and health visitors, raised problems they or local women experienced with maternity services and asked for information about policies and practices in the acute unit. Many of the problems were directed to midwifery managers or consultants.

A fundamental role of health care professionals, particularly midwifery managers and consultants, was to provide information about policies, practices and initiatives. They described policy and practice, explained the rationale behind the provision of services and described the problems they and their staff faced. Their second main role was to respond to problems raised about the quality of maternity services. They made judgements about the validity and relevance of problems and decided whether or not to take action.

Healthcare professionals responded to the views and suggestions made by others about how policies or practices should be improved. They explained the practical ramifications of suggestions. They were the target of consultation themselves when other health professionals visited the MSLC for their views on service developments that would have an impact on their work. They gave these visitors feedback on the appropriateness and acceptability of proposals. In addition, health care professionals had input to the practices of other health care professionals.

In general, the participation of health care professionals was dependent upon the behaviour of other members. They instigated little activity themselves, with the exception of some midwifery managers who reported on initiatives they considered relevant to the MSLC, and community health care professionals such as GPs who raised problems.

There was variation in the input of different kinds of health care professionals. Midwifery managers and consultants were responsible for providing much of the information about policies and practices and responding to problems with hospital services. Community practitioners such as health visitors and GPs raised problems and sought information.

Health authority professionals

Health authority professionals had four main roles: they provided information, responded to problems, led or guided assessment and project work, and consulted the MSLC for its input to new initiatives.

Their main role was providing information. They explained issues of public health, district referral policies and decisions made by the health authority about the funding and development of maternity services. Public health issues included the possible risks to babies of toxins in breast milk. The presence of toxins in breast milk had been reported in the press and was raising anxiety. Public health doctors reassured user members that on balance the benefits of breast feeding outweighed the risks. Health authority representatives also described health service structure and procedures, were a source of information on the effectiveness of health care interventions and explained the impact of new health policies on maternity services.

The second main role of health authority professionals was responding to problems or queries relating to the funding of maternity services or the health authority's referral policies. They clarified the health authority's position and the rationale behind decisions. In addition, they led or co-ordinated some assessment and project work. They produced background papers for the MSLC and provided a route by which MSLC suggestions and recommendations were taken to the health authority. They were a source of knowledge on the likely impact of suggestions for service developments.

Occasionally, they consulted the MSLC or a subset of members for their views on new initiatives, such as whether or not the district should adopt a new national maternity

record. They wanted to know if health care professionals and users considered projects worth funding.

Health authority professionals instigated some work themselves but in general they were reactive to the input of others. There was variation in how proactive they were at reporting public health issues.

Participation in planning and monitoring activity

The previous chapter has shown that the MSLCs had very little input to planning and monitoring the maternity strategy document and health care policies. However, many did attempt to increase their involvement during the observation period. In general, MSLCs were more active in relation to monitoring users' views. The ways members participated are summarised in table 8.2.

User members

User chairpersons were the main instigators of discussions about maternity strategy documents. Other user members were not very involved in discussions about this although they expressed support for greater involvement. A striking exception was an unaffiliated user member (and subsequent chairperson of the MSLC) who was very questioning about the documentation and systems in place and tried to clarify the potential role of the MSLC. In general, user members participated more in discussions about how the MSLC could be involved with planning and monitoring health care. They asked for health professionals to explain documents and processes and asked how they could be involved in developing policies and deciding audit topics.

Table 8.2: Participation in planning and monitoring activity

TYPE OF ACTIVITY	USERS	HEALTH CARE PROFESSIONALS	HEALTH AUTHORITY PROFESSIONALS
Planning and monitoring strategy	Instigated discussions (user chairs); suggested the MSLC should have more input	Contributed very little	Made suggestions for how MSLC could be involved Explained documents and processes; provided relevant documents
Planning and monitoring health care	Instigated discussions (user chairs); requested explanation of planning and monitoring procedures; suggested the MSLC should be more involved	Expressed views on what input the MSLC should have; explained guideline development / clinical audit; brought guidelines to MSLC; reported on audit programme	Described clinical audit and quality monitoring; suggested how MSLC could be involved; provided audit summaries
Monitoring users' views	Set up and ran subgroups, helped to run surveys and other ways of obtaining users' views; reported users' views to health professionals	Helped set up subgroups (heads of midwifery); responded to feedback from users	Collaborated with other MSLC members on surveys / focus groups; helped set up user subgroups

User members were instrumental in monitoring users' views. They set up and ran user subgroups. The user chairperson and user members of one MSLC designed and ran the MSLC's survey of local users. The user chairperson and user members of another MSLC made regular visits to postnatal wards to talk to women about their maternity care. User members reporting the findings of these activities at MSLC meetings.

Health care professionals

Health care professionals contributed very little to discussions about the strategy document. They were much more involved in discussions about MSLC input to the development of health care guidelines. These discussions were usually initiated by other members except in one case where a midwife suggested that user members should be involved in groups developing guidelines (nothing happened as a result).

They contributed by describing the processes that took place in the unit, expressing their views as to whether or not the MSLC should be involved, by bringing in policies, and reporting on the unit's audit programme.

The involvement of health care professionals in the monitoring of users' views was quite limited, with the exception of two heads of midwifery who helped with the user subgroups. Health care professionals gave their views on the implications of the findings of monitoring activities. In two MSLCs, the heads of midwifery took responsibility for providing regular reports of complaints made by users against the unit.

Health authority professionals

Health authority representatives were involved in discussions to do with maternity strategy, quality monitoring and clinical audit. They participated less in discussions about what input the MSLC should have to health care policies. They contributed to discussions about planning and monitoring strategy and health care in three ways: they provided relevant documents such as strategies and service specifications, explained planning and monitoring processes, and in some cases advised the MSLC about what input it could have. A small number provided regular reports about audit activities in the unit. Two public health doctors arranged talks from people in the health authority who had responsibility for planning or monitoring maternity services.

Only two health authority representatives had much to do with monitoring users' views. One helped user members set up a user subgroup and the other had taken on membership of the MSLC in order to promote the input of members to the survey she was planning.

Participation in the running and development of the MSLC

This section looks at how members were involved in determining the structure and procedures of their committees, including their membership, Terms of Reference, annual programme and the content of annual reports. Table 8.3 shows the ways in which the different members took part. Many of the MSLCs reviewed their structure and procedures during the period of observation.

Table 8.3: Participation in the running and development of the MSLC

ACTIVITY	USERS	HEALTH CARE PROFESSIONALS	HEALTH AUTHORITY PROFESSIONALS
Review activity	Instigated and facilitated by user chairperson; organised away days		Led or facilitated review; supported chairperson
Structure (membership, Terms of Reference; arrangements for meetings)	Sought new user members User chairpersons put forward new Terms of Reference; suggested need to tighten up timing of meetings	Helped to recruit new user members	Advised / guided user chairperson on new Terms of Reference
Annual plans and reports	Annual report produced by user chairperson		Instigated voting to choose topics; Produced or helped to produce annual report

Some reviews were scheduled into normal MSLC meetings and others took place at special meetings. In some MSLCs, all members were invited to take part in discussions, but in two committees reviews were conducted by a small core group of members and did not set out to involve everybody. New Terms of Reference were adopted in some MSLCs but there was little discussion of the content of these. There was discussion about MSLC topics in some committees.

User members

User chairpersons instigated and facilitated reviews of MSLC functioning and effectiveness. They set up away days or built discussions into the agenda of the committee, used suggestions in the NHS guidance to facilitate discussions, and produced new Terms of Reference. A user chairperson of one MSLC tried to form ties with a reluctant health authority in order to promote closer links. In MSLCs accountable to trusts, the annual report was written by lay chairpersons. They had little or no experience of writing such documents, but took on the task because there was no one else to do it. In some MSLCs, the report was prepared jointly by the chairperson and health authority representative.

User members were involved in the core groups of some MSLCs that developed annual plans and were instrumental in recruiting new members to the MSLC and user subgroups. User members of one MSLC designed a leaflet to describe and advertise the MSLC.

Health care professionals

Most health care representatives were not very involved in discussions about structure and procedures. The away days of two MSLCs were open to all members but were not well attended by health care professionals. In fact, one meeting did not have any medical representation. Two heads of midwifery expressed reluctance to participate in choosing topics for the MSLC because they thought these should be chosen by user members.

Health authority professionals

In two MSLCs accountable to health authorities the health authority representative led or facilitated discussions about the structure and effectiveness of the committee. They guided the chairperson in producing new Terms of Reference. In some MSLCs, the committee's annual report was prepared jointly by the chairperson and health authority representative. In one MSLC, the public health representative wrote the report.

The interaction between members

In general, meetings had an air of friendliness and good humour, but they were sometimes overrun by antagonism, frustration, anger or blame. It was clear that the work of the MSLC was not a neutral matter to those involved - members were discussing topics they felt passionate about. The following sections look at features of the interaction between different types of members. Extracts of dialogue are provided in boxes. Names have been changed to promote anonymity.

Users and health care professionals

Interaction between user members and health professionals varied from constructive and friendly to hostile and distrustful. Most heads of midwifery, and some midwives and consultants were diplomatic most of the time. A minority were even very positive in their communication with user members, seeking to include them in discussions and keen to hear about problems experienced by local women. Consultants were generally more detached from user members than midwives and did not initiate as much contact with them.

Where dialogue was constructive, health care professionals and user members listened to each other points of view and talked through problems. Discussion was smooth, quick and focused on the problem with maternity care (Examples A and B). Constructive dialogue reflected the fact that users and health care professionals were united by mutual concerns and a commitment to make changes.

EXAMPLE A (MSLC F): Discussion about the benefits of one pain reliever (Meptid) over another (Pethidine) for women in labour. The unit provides Pethidine; the MSLC wants it to provide Meptid.

Midwifery manager: The decision is at the drugs and therapeutic committee. Money is an issue. My view is that you would save money in the long run with Meptid as the epidural rate would go down, and therefore the caesarean rate.

GP: As a committee we can write to suggest that. You Mary (looking at CHC user member) were saying before that we need to be assertive, to pin it down.

CHC user member: I must have had my shoulder pads on that day!

Midwifery manager: Do remember, the drugs and therapeutic committee will be concerned about cost rather than the principle that Meptid is better.

EXAMPLE B (MSLC G): Discussion about which health care professionals would be best placed to ensure women who have had miscarriages do not receive appointments through the post for antenatal care.

User chairperson: It sounds like it needs to be improved, but the question is how.

Head of midwifery: I don't think GPs would be the right people to ensure appointments are cancelled. It would be safer to go through the midwives. There are so many GPs in this area it would be impossible to get to them.

User chairperson: It should go through both. We could memo GPs.

Head of midwifery: Yes, we could just say that the GP or the community midwife is responsible, although there is a responsibility on all of us.

User chairperson: How can we set some action?

Head of midwifery: I can do the internal part of it, talk to midwives and doctors in the unit. Communicating with GPs needs to go through GP organisations.

CHC user member: We could go to GP forums.

Health visitor: We can tackle big chunks of it, but not all of it.

Head of midwifery: That's better than not doing anything.

The interaction between user members and a minority of heads of midwifery, midwives and consultants was less constructive. Health care professionals exhibited a degree of

irritation with user members. This would manifest itself in curt replies and direct challenges to users' views. They also avoided taking the user member's point on board (Examples C and D).

EXAMPLE C (MSLC A): Discussion following a policy change reducing the number of companions during labour (done to promote privacy).

NCT user member: Do women get that information, that it's to promote privacy?

Head of midwifery: They would know that from antenatal classes, although there will be a lag because there will be a transitional period.

NCT user member: The important thing is communication. Women see the notice on the ward about having only one attendant and hackles rise. Could do with written information explaining why it is.

User member: Couldn't we put a poster up in the labour room?

Head of midwifery: [getting defensive] No, there is nowhere for them to go.

User member: There must be some space somewhere.

Head of midwifery: No, you can't. We can't just put information up. There would be a problem with washing down. Information has to be laminated.

EXAMPLE D (MSLC G): User members reporting problems.

NCT user member: Another thing, it is difficult to tell who the staff are, and what grade they are due to them not wearing a uniform.

Midwifery manager: They chose that in the first place! [exasperated]. In a survey a few years ago they preferred that there was no uniform!

NCT user member: They don't know who is who on the wards... can't distinguish between midwives and nursing auxillaries.

Midwifery manager: Doctors, they don't wear white coats! Are women complaining about that?

There was variation in how diplomatic user members were when raising problems with maternity services. In some cases there were long lists of problems to get through. Many user members avoided assigning blame to particular health care professionals but a minority did not flinch from stating who was responsible. However, being tactful did not guarantee a constructive response by health care professionals. Some health care professionals had a manner which suggested they found users generally overly demanding and critical. This was present to some degree in most MSLCs. A user

member suggested it might promote teamworking if MSLC members spent time together in a social capacity. She explained that user members of a neighbouring MSLC organised an annual barbecue. A GP member exclaimed: 'Who do they roast?'

In some discussions it was clear that user members and health care professionals had fundamentally different beliefs about maternity services (Examples E and F).

EXAMPLE E (MSLC F): Different views on birthing pools.

NCT user member: Two couples were told that the pool is only used for pain relief, not birth, that no one has given birth in it yet.

Midwifery manager: The truth is that seven have!

[some confusion about how the couples came to be told that the pool was not used for birth]

Midwifery manager: If I am asked: 'do you advocate water births?', my answer is 'I don't'. I tell women the choices and they decide.

EXAMPLE F (MSLC E): Talking about what choices GPs should offer pregnant women.

Health authority representative: Women should have a choice knowing the risks they are taking choosing home birth.

User member1: Putting it like that makes it sound like a big risk.

User member2: The risks are small.

Midwifery manager: We don't have a problem with low risk women having home births but several high risk women have been saying they want home births.

User member2: I understood we had passed that hurdle! Home births should be given as a choice. Women do not know they are available.

Midwifery manager: If they are low risk, there is still a risk.

Consultant obstetrician: The confidential inquiry shows that there is no increased risk of home birth, but the figure of hospital birth includes a large proportion of high risk women. We all have the same aim, we want to provide a good service in a team for the NHS. We have to provide the greatest good to the greatest number, not a Rolls Royce service to the few!

User member2: Are you saying that women having home births are using too many resources?

There was considerable conflict during discussions about home birth where user members and health care professionals did not agree on its safety. Discussions became polarised and there was little or no room for resolving differences. Health care

professionals vented their anger by arguing that women who wanted home births were using up too many resources and not considering the common good.

Users and health authority representatives (Examples G and H)

Much of the interaction health authority representatives had with user members was with the user chairperson. Two of these relationships were partnerships where the health authority representative guided the chairperson and the MSLC. In a third MSLC, the health authority representative and user chairperson tried to get the health authority interested in the MSLC. In two other MSLCs there were negative elements in the interaction between health authority representatives and user members. In one MSLC (E) there were occasional outbursts of criticism on both sides. Other members looked embarrassed during these incidents. The chairperson found the health authority representative obstructive and the health authority representative was critical of the chairing ability of the chair. A user member attempted to resolve the conflict.

EXAMPLE G: (MSLC H)

Lay chairperson: We do have some very good guidelines which tell us what we and the health authority should be doing. Now, Paul, can you tell us... I know you spoke up very well for us at the health authority, but it fell on stony ground.

Health authority representative: Yes! It explains why I have had frosty treatment since that day! - Incommunicado. The health authority should be leading it, leadership should come from public health. It's pretty intimidating for you to go up against the consultants on a topic like evidence based care on your own.

Lay chairperson: the message from Dr Barratt [director of public health] was: 'don't come here for support, we are busy'. We will keep pushing. Thank you Paul [health authority representative] for your hard work over your time as a member, you have been great fighting our corner at the health authority.

In the other MSLC the health authority representative was often critical of the ideas of the user chairperson and user members. To some extent this reflected her general manner.

EXAMPLE H (MSLC C): The MSLC was discussing a report of an evaluation of maternity care which showed that women were upset that they were made to leave hospital too early. The hospital had recently reduced the number of postnatal beds.

Health authority representative1: If I could just report. There were women who felt pressurized into discharge.. equally, there were some who had felt pressurized into staying!

CHC user member: We are not saying that the system doesn't need flexibility.

Health authority representative1: The majority are happy, Is that not what we should aim for? (rhetorical question).

CHC user member: All women should be happy.

Health authority representative2: That's not realistic (loud and dismissive).

CHC user member: The key issue is flexibility. If you reduce the number of beds, you lose the flexibility.

Interaction between user members

In general there were no tensions apparent between user members at meetings even though at interviews it was clear that there was some tension (see chapter nine). In a few cases, user members cut short the criticisms other user members were making of maternity services or health care professionals. Some user members knew each other well and met together between meetings. Many of the CHC representatives and unaffiliated user members were detached from this core group, sat separately, and raised topics independently.

Interaction between health care professionals (Example I)

In general, midwives and consultants put forward a united front at meetings. However, in one MSLC there were several outbreaks of hostility between midwives and a particular consultant who had different ideas about professional roles and responsibilities. They blamed each other for problems in the unit. Other members appeared frustrated with the arguments and tried to curtail them.

EXAMPLE I (MSLC G): Interaction between health care professionals.

User chairperson: Is the postnatal check done by midwives now, rather than paediatricians?

Midwifery manager: Yes, well it will be, we need training.

User chairperson: What about the delay in waiting for a paediatrician to turn up to do the postnatal check before a woman can be discharged?

Consultant paediatrician: This should be an internal matter. The Senior House Officer charts are badly organised by the midwives: that is why the check is not done when a woman wants to go home.

Midwifery manager: There is no flexibility with the paediatric staff. Women may decide on a particular morning that they want to go home, so we can't preorganise the charts! [Exasperated.]

Consultant paediatrician: Midwives conducting baby checks needs careful evaluation before it is implemented, for two reasons: it needs to be effective, and there are implication on the training of paediatricians.

GP: Can I clarify - I am not assigning blame - but why can't midwives be trained up also?

Consultant paedatrician: The training is not by the Royal College, but is at (a nearby hospital). The Royal College does not provide training.

GP: We do not have to wait for the Royal College to make a pronouncement. That's not how we work in other things. ... With respect Peter (consultant paediatrician) professionals need to get together to sort it out so that midwives can do the checks.

Consultant paediatrician: With respect Charles [GP]...

GP: [cutting consultant off] No! *My* comment was 'with respect!'

Midwifery manager: Midwives are independent practitioners, they are not nurses working for doctors. If they wish to extent their role they can.

The relationship between health visitors and midwives was sometimes problematic. There was the potential for frustration they experienced working with each other outside the MSLC to manifest at meetings. The health visitor of one MSLC was very vocal about problems health visitors experienced with midwives, and midwives on the MSLC were resistant to taking on board her input. In another committee, the head of midwifery and the community services manager (manager of health visitors) were careful to say positive things about midwives and health visitors working together. It was clear from comments they made outside meetings that their staff did not share the same degree of mutual respect.

Health care professionals and health authority representatives (Example J)

The interaction between health care professionals and health authority representatives was generally neutral or friendly, but was occasionally marred by frustration on the part of health care professionals when they felt that the health authority was obstructing their ideas for improvements to maternity services. It seemed that resentment and anger were ready to surface as soon as issues about funding or quality monitoring were raised. Health care professionals directed their frustrations at health authority representatives who in turn became irritated about being blamed for the decisions of the health authority.

EXAMPLE J (MSLC D): Irritation with the health authority representative.

Chairperson: John (Trust business manager) can you update us on the situation with the breast feeding counsellor?

Trust business manager: There has been minimal progress on that. I was wondering if as a parting shot Jane (the public health representative) could sort it out! (loud laugh from him and from around the room).

Summary of main points

User members, health care professionals and health authority representatives had different roles on their MSLCs. Users raised problems and sought information while health professionals provided information. Health care professionals described and explained policy and practice and health authority representatives did the same in relation to health authority decisions and public health issues. Each group was a gatekeeper for a different kind of information: users had knowledge of the experiences of local women, and health professionals knew about the policies, plans and workings of their organisations.

There was a difference in how active users and health professionals were on the MSLCs. In general, user members were more active than health professionals. They raised topics and requested information and user chairpersons conducted MSLC work and instigated and facilitated the reviews of MSLC effectiveness. Many health care professionals were more passive, providing information only at the behest of other MSLC members. Health authority representatives were split into two groups: some initiated discussions and work, and others were more passive.

Chapter nine:

The views and experiences of MSLC members

Introduction and summary

This chapter describes the views and experiences of the 40 MSLC members who were interviewed. The first three sections describe their background, their motives for involvement and their experiences of MSLC meetings. Subsequent sections look at what members considered to be the purpose, achievements and shortcomings of their committees. The final section assesses how worthwhile overall respondents found their committees.

Most user members had extensive networks with user organisations and local women and some were involved with other initiatives in maternity services. They were involved with the MSLC out of a desire to improve specific aspects of maternity services or to develop processes for user involvement in maternity services. Most of the midwives and consultants had substantial managerial or clinical responsibilities. Like health authority members they had no choice about their membership, but most had interests which they hoped to pursue through the MSLC. Non-managerial health care professionals and GPs were keen to be involved in order to keep in touch with service developments.

While members felt that committee meetings were generally friendly, most members experienced background tension. Users expected some antagonism from health professionals; health professionals were concerned that other members might criticise maternity services or their colleagues; and health authority respondents felt they were

in danger of becoming the target of other members' frustrations to do with funding decisions made by the health authority.

Most respondents regarded the purpose of the MSLC as promoting a multidisciplinary approach to maternity services. They saw it as a forum to facilitate communication between stakeholders. Achievements and benefits they identified included improvements to specific maternity services and changes to attitudes, promoting the user perspective in maternity services, keeping members informed, developing the MSLC itself, and promoting the external scrutiny of health care. Shortcomings and problems were to do with deficiencies in the representativeness of members, the behaviour and attitudes of members, a lack of purpose on the MSLC or an inappropriate remit, problems with committee functioning, and a lack of power to influence maternity services.

The majority of respondents considered their MSLCs worthwhile despite experiencing frustrations and reporting substantial shortcomings. The minority who did not think their MSLCs worthwhile were particularly exasperated with what they saw as the inappropriate demands of user members.

* * * * *

The background of respondents

The table below shows the number and background of respondents in each constituent group interviewed. The distribution of respondents across MSLCs is shown in table 5.4 in chapter five.

Table 9.1: The background of respondents

CONSTITUENT GROUP (number)	BACKGROUND OF MEMBERS
Lay / user members (8)	4 NCT 2 user subgroups 1 CHC 1 unaffiliated (both the CHC and unaffiliated representative took over the chairs of their MSLCs at the end of the observation period)
Chairpersons (8)	2 non-executive directors of the health authority 2 CHC members (one co-chair) 3 NCT members 1 consultant obstetrician (co-chair)
Healthcare professionals (17)	10 Midwifery members: (8) Heads of midwifery (1) Project midwife (promotion of Changing Childbirth) (1) Community midwife 4 Consultants: (3) Obstetricians (1) Neonatologist 2 General practitioners 1 Health visitor
Health authority (7)	3 public health consultants 2 nursing and professional advisers 1 commissioning manager 1 manager of extra contractual referrals

User members

Most user member respondents had extensive networks with user organisations and local women. Several were active members of both the National Childbirth Trust (NCT) and Community Health Council (CHC). The NCT members ran antenatal classes and

provided breast feeding counselling. Some were involved with other initiatives and committees in maternity services, including a *Changing Childbirth* steering group, a maternity services strategy group and a working group aiming to promote breast feeding.

Most had been MSLC members for between one and three years. One had been involved for eight years, although she had represented different constituencies during that time. Most had used local maternity services, although only two of them had done so recently. The first was planning her second home birth and the second had spent many weeks as an inpatient in the local unit prior to the birth of her baby by caesarean section.

Half the user representatives were raising their children full time. The other half were working full or part time in a variety of occupations, including chartered accountancy, running a nanny agency and auxiliary nursing. The majority lived in prosperous areas.

Chairpersons

Chairpersons who were interviewed varied in age and background. The non-executive directors and CHC members were over fifty, with grown-up children. The three NCT members were younger and had younger children. One of the co-chairpersons interviewed was a consultant obstetrician. In this chapter, his views are described with those of other obstetricians.

Healthcare professionals

The health care professionals interviewed had been MSLC members for between two and nine years. The longest serving members were consultants and GPs.

The heads of midwifery were responsible for the work of midwives in the acute trust and the community, and over half also managed gynaecological services. One was the associate clinical director of women's services. Two of the four obstetricians were clinical directors (one was the MSLC co-chair). The community midwife worked in several general practices and had a base in the local maternity unit.

The GPs had more experience of maternity care than is usual among GPs. They provided antenatal and postnatal care and one also took responsibility for the intra partum care of her patients in the local trust. The other had worked in the local obstetric unit as a registrar. The health visitor had been a midwife in the local unit some years ago, prior to retraining.

Health authority personnel

Health authority respondents had been involved for between six months and over four years. The MSLCs varied in the length of their association with their health authorities. Two MSLCs had only recently opened up their membership to the health authority. The public health members had been involved for longer than the commissioning and extra-contract referral managers.

Some health authority respondents had experience of working as healthcare professionals. The two professional and nursing advisers were trained nurses and the

manager of extra-contractual referrals had trained as a midwife, although she never practised.

Motivation for involvement

Respondents were asked why they became members. Clues to their interests and motives were also found elsewhere in the interviews. The box below summarises respondents' motives.

Box 9.2: Summary of the interests and intentions of members

<table>
<tr><td>USER MEMBERS</td><td colspan="2">HEALTH AUTHORITY MEMBERS</td></tr>
<tr><td>To report women's views and experiences
To raise topics of national and local importance
To act as a link between the MSLC and user organisations / groups they are involved with
To maintain and improve user input</td><td colspan="2">To promote effective care
To promote consumer input
To guide or direct MSLC development
To develop constructive relationships with health care professionals</td></tr>
<tr><td colspan="3">HEALTH CARE PROFESSIONALS</td></tr>
<tr><td>Midwifery members
To use the MSLC as a lever for promoting change in the unit
To represent practising midwives</td><td>Midwives and consultants
To hear and respond to others' views on services
Health visitor
To raise problems with maternity services</td><td>GPs
To be informed about policies and practices
To act as a link between GPs and the MSLC</td></tr>
</table>

User members

User respondents fell broadly into two categories: those who were predominantly focused on specific aspects of maternity care or reporting problems local women experienced, and those who were interested in these, but also had a desire to see

more systematic user input to planning and monitoring processes in maternity services.

> 'Mostly you are there raising an issue, saying this issue matters, people want to know about this. You are there for the three and a half thousand women a year who have babies in this district, who are not going to make a complaint, but who were not happy with aspects of their care. You won't raise all the individual ones - a lot of those will be very subjective - but you will raise the ones that are important. I think that is why I am there.' (User member, MSLC A)

Many user respondents were interested in 'biting locally on national issues' such as the rise in caesarean sections and deficiencies in postnatal care. They aimed to 'bring these issues forward and ask [health professionals]: "What are you going to do about it?" '. Those members who represented user organisations or groups considered they had a duty to ensure a two-way flow of information between the organisation and the MSLC. They aimed to raise issues important to their organisation with the MSLC and report back to the organisation on MSLC business. In addition to all the other reasons for involvement, many user respondents described a sense of duty to maintain the user presence at meetings as this helped to 'chip away at old fashioned attitudes'.

> 'I want to see more change in attitude, more recognition that attitudes need to change, albeit slowly. No one is saying that all of a sudden everyone should wake up and smell the roses or whatever, just that more views should be listened to.' (User member, MSLC D)

Health care professionals

Midwifery staff

The heads of midwifery were members because it formed part of their management responsibilities. While they did not have any choice about their membership, most had interests which they hoped to pursue through the MSLC. They were interested in hearing feedback from user members as it provided a gauge of local opinion. They wanted to be present to respond to the concerns of users. Some valued the opportunities the MSLC provided for them to see the service from a fresh perspective

and valued the MSLC as a potential source of support for initiatives they were planning.

> 'I came into a unit which had a reputation for not having a good relationship with its MSLC internally. It was also renowned for a lot of interventions - a lot of interference in childbirth. Part of my remit when I was given the job was to alter all this! I actually had a very nice meeting with the lay members and there was a real sense that we wanted the same things.' (Head of midwifery, MSLC G)

The community midwife was a member out of choice. She wanted to represent the views of 'ground floor' midwives, which she did not think could be done by midwifery managers.

Consultants

Some consultants also had little or no choice over their membership. The paediatrician became a member by default because he was the only neonatologist in the unit at the time such representation was sought by the MSLC. One of the obstetricians had a special interest in antenatal screening which was of relevance to the MSLC, but she recognised that she was largely there by default because she was new and other obstetricians had already been members or were not interested. A second obstetrician was clinical director and saw it as part of his management responsibilities.

They all thought it important that they should be on the MSLC, if only to 'nip unrealistic ideas in the bud'. However, others were motivated by more positive interests and they saw the MSLC as a useful source of feedback on services. One of the consultants had used the MSLC to raise problems he was having with midwifery colleagues in the unit, even though he did not consider this to be an appropriate use of the committee.

General practitioners

The two GPs were voluntary members, involved because of their desire to keep in touch with hospital policies and practices. These were directly relevant to one GP as she occasionally delivered babies (of her patients) in the hospital. The other GP tried to act as a link between the unit and local GPs. She reported on MSLC business to the local division of GPs and raised queries on the MSLC reported to her by local GPs.

Health visitor

The health visitor had first become concerned about practices in the local unit while working there as a midwife. Feedback from her patients indicated that the same problems still existed and she aimed to bring these to the attention of health care professionals through the MSLC.

Health authority

Most health authority representatives were involved because they had responsibility for maternity services in the health authority. Some of the public health doctors and both the professional advisers were responsible for maintaining and developing the MSLC. Most of the health authority respondents thought the MSLC was potentially useful to them. They thought it could help them to improve their relationships with health care staff, which had suffered in the past as a consequence of the purchaser-provider split. They also saw the MSLC as a potentially useful forum for promoting evidence based practice. They aimed to report to the MSLC any relevant national issues and research findings and keep the MSLC up to date with the health authority's position on maternity services.

Experience of MSLC meetings

Respondents were asked what the meetings were like and what it felt like for them to be there. The majority of members made positive comments about the general tone and atmosphere of MSLC meetings. They found the meetings friendly, informal and open. They said that meeting over lunch helped to promote this. A minority went so far as to describe the meetings as interesting and enjoyable. A GP said meetings were 'pleasant to go to insofar as you feel able to talk, to express your thoughts, and that's important.'

Most members also described frustrations and tensions that they experienced at meetings. These are summarised in the box below.

Box 9.3: The tensions experienced by respondents

<table>
<tr><th>USERS</th><th colspan="2">MIDWIVES</th><th>CONSULTANTS</th><th>HEALTH AUTHORITY</th></tr>
<tr><td>Expectation of a degree of negativity from others

Moderating own input to reduce antagonism

Awareness of undercurrents amongst other members</td><td colspan="2">Balancing openness and loyalty to staff</td><td>Antagonism about inappropriate attempts to influence healthcare</td><td>Tension with other members because of the health authority's power over funding

Frustration directed at them because of lack of resources</td></tr>
<tr><td colspan="4">Danger of gratuitous criticism of healthcare professionals

Awareness of a lack of support for the MSLC among their colleagues outside the committee</td><td></td></tr>
</table>

User members

Half the user members expected the issues they raised and the problems they reported with local services to be met by a degree of negativity from health care

professionals. One described the situation as 'treading on eggshells.' A second explained that it was nearly impossible to avoid a degree of antagonism on the part of healthcare professionals: 'They are extremely defensive and it is very difficult for us to raise an issue in a way that doesn't make them defensive about the job they are doing'. Even those with substantial experience of committees and campaigning were apprehensive about putting forward views that they knew to be at odds with those of health professionals. Some users described substantial feelings of intimidation. They felt the healthcare professionals exhibited contempt towards them for having to bother informing users about their practice. Another user member said that consultants never addressed users directly and this made her nervous about directing questions to them:

> 'It would be difficult, but I could do it. I would have to take a couple of deep breaths and compose myself. Have you noticed that I stutter more at meetings? I feel nervous, terribly nervous there. I do a bit of yoga before I go in!' (User member, MSLC D)

Some user members were aware of undercurrents and tensions in the relationships between health professionals and tried to avoid saying something which might key into these.

Health care professionals

Many heads of midwifery experienced some tension linked to the potential for criticism of services and staff. They were aware of a need to ensure that any problems to do with maternity services were talked about constructively and in a way that did not undermine loyalty to their staff.

Some consultants experienced frustration in relation to what they saw as misguided attempts to influence clinical policies and practice and monitor their practice. They were insulted by what appeared to be the assumption of others that 'we wouldn't be

providing a proper service unless they [the MSLC] were checking'. Others felt they were wasting time on MSLC projects when it was unlikely there would be any funding from the health authority to implement changes.

Some heads of midwifery were concerned about being 'put on the spot' and having to explain incidents or problems experienced by local women. Others were concerned that the meeting could turn into 'health professional bashing'. They did not think user members appreciated the difficulties inherent in their work and the competing constraints that are on them with regard to provision of the service.

> 'I sometimes feel like taking my badge off and putting it on the table and saying: 'look, if you can do a better job..', it almost feels like that. But it's partly because of what day it is. I may have had a busy week, babies dying and all this, which seems to go totally unnoticed. It's like they are focusing on this little bit of what happens.' (Head of midwifery, MSLC C)

Some midwives and consultants were aware that their midwifery and medical colleagues had negative views about the MSLC and about user involvement in general. One consultant said: 'They [MSLCs] are not held in esteem; there's great reluctance to spend time on them as it's seen as time not well spent.' They did not think other MSLC members appreciated the extent of this negativity.

Health authority

Some health authority members experienced a degree of tension in their relationships with other MSLC members because of the power the health authority has over the funding of services. Public health consultants found that health care professionals directed the anger they felt about a lack of funding to them personally, even though they had very limited power to influence funding decisions. Most health authority respondents felt that other MSLC members did not appreciate that maternity care was only a small part of their work and that maternity services were no longer a priority of

the health authority. Some respondents perceived a potential source of conflict between the way user members represented the needs and wants of certain subgroups of the population and the way the health authority had to take a wider population perspective:

> 'There are two ways of looking at users. There are the individual users who have their particular wants and needs and then there is us as commissioners looking at users en masse, a population, what we can afford in the best interests of that population. There is always that difficulty.' (Public health consultant, MSLC A)

The purpose of the MSLC

Respondents were asked what they saw as the purpose of the MSLC. Most members thought that a fundamental purpose of the MSLC was to involve users, but what user involvement would amount to was described in modest terms. One health professional said the MSLC 'enabled users' views to be heard'. Others focused on the interaction between users and health professionals:

> 'Its meant to be a liaison committee - literally a joining together: liaisons dangereuses! - where the two sides meet and discuss issues of joint interest, whether it is about doctors, whether the food is bad, whether the help with the breast feeding is good enough; whether we want to introduce something new... all the important issues.'
> (Consultant obstetrician, MSLC A)

More ambitious definitions included that given by a head of midwifery who said that the MSLC should act as 'one of the bridges over the gap between what we are providing and what women actually want.' Many users and a small number of health professionals saw the MSLC as a forum to challenge health care practices and open up debates to a wider audience.

> 'I think the problem with health professionals, like a lot of other professions, they are very close knit and sometimes they are very protective of themselves. Having worked in the health service I know it can be a very closed book... if things go wrong. Users are not paid for what they are doing, they are voluntary. They don't have to be frightened of speaking their minds to fit in with their colleagues, or their boss, or the health service really.' (User member, MSLC H)

In addition to user involvement, many respondents also described the promotion of multidisciplinary working as a purpose of their MSLCs. A midwife described the MSLC as a 'communication process'; another member said the MSLC was a 'central forum for discussion and useful to help all sides understand what is happening as much as anything'. A GP described the purpose as co-ordinating the people who each provide a small part of maternity care for women.

A minority of respondents (mostly user members) described the fundamental purpose of the MSLC as promoting substantive changes to maternity services. Most of the other respondents thought that the promotion of multidisciplinary working would lead to improvements, but did not regard the MSLC as having a more direct role in developing maternity services.

Achievements and benefits

This section describes the achievements and benefits reported by members. They have been grouped by the author into six categories as shown in Box 9.4.

Some members found it difficult or impossible to think of specific achievements and talked only of benefits such as the promotion of multidisciplinary working. Others described these same benefits as achievements. Most members reported achievements or benefits in two or three areas. In most areas, midwives and users reported the most achievements or benefits and consultants reported the least.

Box 9.4: Achievements and benefits reported by respondents (ordered by frequency of report)

CATEGORY	ACHIEVEMENT / BENEFIT
Changes to maternity services	Specific change to maternity services Influence on culture and attitudes Provides support to health professionals
MSLC development	Improvements to MSLC structure and functioning Improved user involvement
Provides consumer perspective on maternity services	Identifies problems with healthcare Provides complementary perspective Enables consultation of users in relation to specific developments
Promotes multidisciplinary working	Provides more holistic appreciation of the service Provides a fuller appreciation of problems and possible solutions Promotes inter-professional working
Provides external scrutiny	Promotes external scrutiny of healthcare and the accountability of healthcare professionals Provides impetus for change
Informs about maternity services and their development	Informs users, healthcare professionals and the health authority Promotes mutual understanding and accountability

Changes to maternity services

Just under half the respondents reported that MSLC work had contributed to the improvement of maternity services. The impact was in relation to specific maternity services or to the attitudes of health professionals.

The impact on specific services was described in modest terms. In some cases, changes to policies and practices could be recalled, but respondents frequently found it difficult to identify the exact contribution of the MSLC. A health authority member explained that when a topic became a concern of the MSLC, this provided health care professionals with the impetus to do something about it. A user described how 'us rattling on and on about the lack of consistent advice' had promoted the

implementation of training for midwives. A health authority respondent explained that: 'If child health surveillance hadn't come to the MSLC, it would have rumbled on until somebody fell through the net.' Some health professionals had found the MSLC a useful source of encouragement and support for pushing forward service developments. They had used the MSLC as a 'tool to face the brick walls put up by other health care professionals.' The MSLC was also a place to thrash out ideas and get valuable feedback on plans for new initiatives.

> 'If you think you've got some ideas that you want to push forward, it is an opportunity to sound out how the purchasers and others feel about it. The breast feeding clinic was a good example. I don't think maybe we would have started that if we hadn't had that group to give us a bit of support and feedback including pulling the NCT breast feeding counsellors in.' (Head of midwifery, MSLC F)

It was mostly user respondents who mentioned achievements to do with changed attitudes. They thought some health care professionals had become more receptive to users' views. A head of midwifery explained how the MSLC had helped her to sell changes in midwifery practice to previously resistant local GPs.

MSLC development

Just over one third of respondents considered improvements to the MSLC itself to be achievements. User members and some midwives felt that changes to the membership and the introduction of lay chairship had promoted better user involvement and reduced the way meetings were dominated by the interests of healthcare professionals.

> 'I think the fact that it has gelled and is working well. I think that's an achievement and I think that's the new lay chair. The previous chairperson was very good but I think the new one has pulled it into a different sort of group. The fact that people turn up regularly and you know there's no problem with people coming into the group. I think it's to do with chairship style. And allowing people to say what they think.' (Midwifery member, MSLC F)

Some members considered the setting up of new user subgroups to be an achievement. A health authority respondent felt that this reflected a shift in attitude among health care professionals towards users: 'The subgroup is working well and the trust aren't seeing it as a threat - they are working with it'.

Provides the consumer perspective on maternity services

Just over one third of members reported benefits arising from the involvement of users. The most frequently reported benefits were to do with users providing feedback on local services. A midwife explained that the feedback provided 'some sort of route into problems that can be followed through'. Respondents felt that the MSLC encouraged health professionals to stand back and take a fresh look at the services they provided. This provided an antidote to their over-familiarity with the environment.

> 'When somebody comes in as a patient it is foreign territory, everything is new, they don't know what is round the next corner. I think it is important to be able to take people who work there all the time and see thousands of mothers, to take them back to see how it feels for each individual, try to get them to imagine if they were in the patient's place why things might be a problem.' (User member, MSLC C)

The MSLC was seen by some health professionals as a convenient place to consult users about specific initiatives they had planned. It also provided a 'bank' of user representatives who could be contacted outside the committee.

> 'So achievements have been: we would have done the questionnaires and the birth plans without the MSLC but they [user members] have had input. We wrote a birth plan and then gave it to user members to read and of course they scrawled it all through, saying this is terrible, terrible; and so I said why don't we meet and write it together, which was a much better way of going about it. If we had not had that venue to take it to we would probably have been in danger of implementing something without proper consultation.' (Midwifery member, MSLC F)

Promotes multidisciplinary working

Just under one third of members reported benefits to do with multidisciplinary working. The MSLC provided opportunities for health professionals to meet who did not meet elsewhere. As a result, they were able to iron out problems between primary and secondary care and between different professional groups.

> 'It is a forum whereby there is such a cross section of people that you can look at the whole service, it is not just the hospital side of it, it is the community, it is the whole thing: social workers, health visitors. The whole remit is in one room. What is okay for me, might not be okay for the health visitors and so they give their viewpoint. You get a good overall picture.' (Head of midwifery, MSLC D)

Some respondents thought that discussions on the MSLC promoted a more holistic appreciation of problems and possible solutions than would be gained by any group independently. Most respondents saw user members as an important party in these discussions. A midwifery manager explained how the MSLC promoted understanding of unresolved or controversial topics.

The MSLC provides external scrutiny of health care

A benefit reported by a quarter of the respondents related to how the MSLC promoted external scrutiny of maternity care. They thought that this provided health professionals with the impetus to resolve problems. A user respondent explained how the MSLC 'provides another dimension to the cosy professional club', opening up debates about practices to a wider audience. A head of midwifery called her MSLC a 'watchful eye on maternity services' and regarded the presence of the health authority important to this function:

> 'Because of its health authority status, it's actually in a very important position. It should be able to have an ability to have a credible board type view about a maternity service, whether it's positive or negative. If we were such a dreadful service it would presumably have a view about what needs to be done to make the service better.' (Head of midwifery, MSLC E)

On a more personal level, another head of midwifery explained how the external scrutiny 'keeps you on your toes, and that's how it should be.'

The MSLC informs members about maternity services

Approximately one fifth of the respondents reported benefits to do with how the MSLC kept members informed about maternity services. A user described the MSLC as an important hub in passing on information:

> 'Everybody has access to this central point for information. Information is put at the foot of the MSLC so all those involved have access to it.' (User member, MSLC D)

Another user member described the MSLC as 'one way of ensuring the public is informed about what the service is about.' The GPs and the community midwife found the MSLC beneficial for keeping them informed about developments that might have a bearing on their work.

This information-giving role of the MSLC was valued in itself but was also seen as an important prerequisite to acquiring a comprehensive understanding of the complexities in healthcare. It could correct wrong assumptions and resolve potential problems that might otherwise turn into complaints.

Shortcomings and problems

The shortcomings and problems reported by members have been grouped by the author into five areas and these are shown in Table 8.5. Most people described shortcomings in more than one area.

Table 9.5: Shortcomings and problems reported by respondents (ordered by frequency of report)

CATEGORY	SHORTCOMING / PROBLEM
Shortfalls in representation	Weaknesses in the representation of users and health professionals
Problems with the behaviour and attitudes of members	**Health professionals**: poor attendance and commitment; lack of openness; denial of problems **User members**: overly critical; focus on personal issues; breach confidentiality
Inadequacies in the remit of the MSLC	Lack of purpose Inappropriate remit in relation to clinical care or operational aspects of the service
Deficiencies in committee functioning	Poor management of meetings; deficiencies in agendas; meetings too infrequent; inadequate dissemination of information
Lack of influence in maternity services	Lack of power to influence decisions in the health authority and trust; poor links between the MSLC and decision making processes; lack of will on the part of health professionals to promote MSLC interests

Shortfalls in representation

Problems with the representation of users

Over half the health professional respondents thought there were problems to do with user representation. Their main concern was that users did not represent typical users because they were predominantly white and middle class and interested in fringe matters such as home birth. They were not seen as representing minorities or socially

> 'They are people who are highly articulate and motivated and they are not from... the areas of social deprivation, so what they want is not necessarily representative of women. They are a highly selective group, but that's inevitable because you are not going to get someone who left school at 15, got pregnant at 16, perhaps been a drug user in the past, volunteering to come forward on one of these committees. I think some of the main aims and objectives are what most women would want and would welcome but there are those where it's rather more specifically the NCT clientele... it's their views, rather than the views of the average woman that I see in antenatal clinics.' (Consultant obstetrician, MSLC A)

deprived women. Some members thought there were inherent limitations to how representative members could be because membership only appeals to outspoken women with strong views.

A small number of health professionals were also critical of questionnaire surveys, focus groups and user subgroups for being subject to the same selection bias. They felt that their own day to day contact with patients in the course of their work meant that they were more in touch with the 'typical' user and what local women want from maternity services than user members.

A small minority of health professional respondents had concerns that the user members were not adequately trained up for their role and did not network well with other user representatives or local users.

Some user members also had some problems with the ways users were represented. They did not think it appropriate that the MSLC should have non-affiliated users as members as they focused too much on their own issues and experiences and did not have adequate contacts with local women.

Some user and midwifery respondents considered it inappropriate that their MSLCs were chaired by non-executive directors of the health authority or older women who had not used maternity services for some years. They thought their committees should be chaired by recent or present users of the service who were independent of the health authority.

Problems with the representation of health professionals

Most of the user respondents and a quarter of health professionals reported shortfalls in the representativeness of health care professionals, particularly that of GPs and consultants. Midwives and consultants thought that the GP members were not typical of most GPs because of their high level of interest in maternity services and desire to maintain GP input to maternity care. In addition, the ability of GP members to represent the views of a wider constituency was considered to be limited by the lack of adequate networks between GPs.

With regard to consultants, some respondents felt that their professional independence made it difficult if not impossible for one consultant to speak for all consultants in the unit. Some members saw their consultants as atypical of the consultant body because they were more positive about the MSLC and user involvement and more keen on making changes.

> 'At the end of the day I think did we achieve much? We may have a policy, but I'm left wondering... out of all the consultants in the unit, I know at least one won't agree with it.' (Health visitor, MSLC H)

A small number of respondents mentioned shortcomings in relation to health authority and midwifery representation. This included consultants who thought the health authority representation too junior to have any real influence in the health authority and users who felt that there was insufficient input from practising midwives.

Problems with the behaviour and attitudes of health professional members

Most users and some health professionals reported that MSLC work was hampered by the poor attendance of healthcare professionals. The main concern was that consultants failed to turn up to meetings or attended only parts of meetings. User

respondents felt that their absence reflected a lack of engagement with the principles of user involvement and the work of the MSLC. A GP explained that the time she spent at meetings was wasted if the consultant did not turn up because most of her queries were to do with obstetric matters.

Some user respondents felt that there was reluctance on the part of health care professionals to inform them about healthcare practices and initiatives, so that by the time they found out about initiatives it was often too late for them to have input. Where the health professionals did inform the committee about services they did so in such a way as to gloss over problems and show the service in the best possible light. User members became suspicious when these reports did not correspond with what they heard from local users and other midwives.

> 'I do feel there is a real tension between what really goes on and what the trusts feel that they have to present. It would be better if the professionals were more open about the problems that they knew were going on and then we could all acknowledge them together and there would be more of a feeling that we were all working in the same direction.' (User chairperson, MSLC C)

Many users were concerned about the way midwives and consultants avoided taking on board problems they raised, either by denying the problem or explaining it away as an insignificant or acceptable aberration given the lack of resources available.

> 'They deny it, or they try and find some excuse to explain it away, like, that one was a particularly difficult woman, or it was a particularly busy shift; or there was some practical thing why they couldn't do it.' (User chairperson, MSLC G)

Problems with the behaviour and attitudes of user members

Half the midwifery managers and consultant respondents reported problems to do with the behaviour of user members. Many found it disheartening that the users focused

solely on problems or peripheral aspects of the service and failed to recognise the good practice.

> 'It seems they don't grasp the enormity of the service and look at just one little bit of it. So they repeatedly brought up disability access almost ad nauseum and the staff got quite upset about that because they feel that no one acknowledges the pace of their work anyway. I don't think they've got any comprehension of how difficult it is to run this service on a day to day basis.' (Head of midwifery, MSLC C)

They felt that personal stories or individual cases took up too much MSLC time. They were also concerned about the potential danger of compromising the anonymity of staff and women if the case was detailed or unusual. They also thought that some user members spent too much time on fringe interests such as home birth, which health professionals did not consider to be of interest to most women.

Inadequate or inappropriate MSLC remit

Over half of those interviewed felt there was an absence of purpose to the MSLC. Some attributed this to the MSLC failing to establish a new direction when work to do with *Changing Childbirth* tailed off and others thought it was due to the committee's preoccupation with its own structure and functioning. However, some considered it to be a longer standing problem. A midwife described how members were 'sitting there, thinking what on earth am I doing here?'

Respondents felt that the lack of purpose resulted in the meetings being highjacked by whatever topics happen to be raised that day. Without an adequate strategy or plan of work, the work of the committee could easily be swayed by the interests of a vocal subgroup. Some health professionals were concerned that the meetings were taken up with the preoccupations of user members. In part this was attributed to the inertia of healthcare professionals with regard to raising issues or topics they knew to be important.

Over a quarter of the members reported problems with the role their MSLC was trying to establish. Several of the MSLCs conducted reviews of their structure and functioning during the observation period in response to the launch of the NHS Executive guidelines (NHS Executive 1996). Members of the same committees had different views on what the remit of their MSLCs should be and how the NHS Executive guidelines should be interpreted. Some health authority and healthcare professional members wanted the MSLC to be predominantly concerned with strategy. Involvement with operational issues was considered inappropriate or only of secondary importance.

A major concern of some health care professionals, particularly consultants, was that user members were attempting to adopt an inappropriate degree of influence over the content or delivery of clinical care. They did not consider users had 'sufficient knowledge and experience to understand the things that are implicit in guidelines on medical practice', and felt they did not appreciate the legal responsibility carried by healthcare professionals.

> 'Using screening as an illustration, what I feel is that as professionals, we should be allowed to provide screening in what we consider to be an appropriate and professional way, taking on board the views of user members but without a list that says you've got to do every one of these single things. I don't see that we actually gain anything by doing that - it becomes regimented and list orientated and loses the essence of clinical communication.' (Consultant obstetrician, MSLC E)

From the health authority point of view there were some concerns that the MSLC focused only on the main trust, even though the committee should be concerned with other maternity units with which the health authority has contracts.

Deficiencies in committee functioning

Just under half the respondents reported problems to do with the functioning of the committee. Committee discussions were seen as unfocused, overlong and repetitious, or dominated by certain individuals. Health professionals considered the problem was

exacerbated by the lay chairperson's inability to control discussions and draw out agreement and action points. Some respondents thought the MSLC was not adequately involving all members as the agenda did not ask for reports from all constituent groups. Some of the respondents on committees that met every six weeks thought this was too infrequent. They felt it was not conducive to teamwork and maintaining the impetus of work.

Some user respondents thought the MSLC was very poor at ensuring relevant documents relating to local healthcare and national initiatives were brought to the attention of the committee and adequately distributed to members.

Lack of influence in maternity services

A shortcoming mentioned by one in four respondents was the lack of MSLC influence on relevant decision making processes in the health authority and trust. Having no power to ensure its suggestions were taken on board nor any say in how the health authority or trust allocated funds, the MSLC was felt to amount to no more than a 'talking shop'. Some respondents felt the problem lay in the lack of effective communication between the MSLC and people in the health authority or trust who make the decisions. A health authority member explained that the absence of effective communication was in part due to the health authority's uncertainty about how to relate to the MSLC. The health authority's usual link with advisory committees in the district was to have an executive director in the chair. As this was not the case with most MSLCs, there was no direct link with between top management and the MSLC. Some respondents considered the problem to be a lack of commitment in the health authority or trust to incorporating the ideas of the MSLC.

'I think the MSLC lay membership doesn't have the power it needs to have to get real change. The Trust can consult but it doesn't have to take on board. The Trust can choose not to get in touch with them. I think the systems are there already to make use of, if people would take more note of them. If you consult and don't do it then you are wasting everyone's time and effort.' (Community midwife, MSLC B)

Some blamed particular individuals on the MSLC for not exercising the power they possessed to influence their colleagues or promote issues within their organisations.

Respondents' assessments of the overall value of their MSLCs

Most respondents reported substantial shortcomings and problems to do with their MSLCs. The extent to which these were considered so serious that they compromised the overall value of the MSLC depended on how much they valued the achievements and benefits. Of particular relevance was the extent to which they thought user involvement through the MSLC was important, how much they valued the less tangible benefits of the MSLC and the extent to which they thought the MSLC could improve. Most respondents appeared to concur with the comment of one midwife that: 'MSLCs are important but not achieving loads'.

User respondents

User members had major concerns about the extent to which their MSLCs had an impact on maternity services and were frustrated by the many barriers to getting their views taken seriously, but they continued to be involved because they couldn't see any other way of addressing what they saw as major deficiencies in maternity services. They felt that by badgering away they had helped to promote some small changes to services and hoped that keeping the user presence high on the agenda would promote changes in the attitudes of health professionals in the MSLC in the longer term. They hoped the MSLC would help to promote woman-centred services where health

professionals would be more open and accountable to users and where it would be natural and automatic for them to consult users when they make changes to services.

They valued the opportunities MSLCs provided to promote multidisciplinary working as they felt a lack of co-ordination was responsible for a lot of problems in maternity services. Even if the MSLC was not presently achieving very much in terms of improvements to maternity services, it provided information and kept people informed about maternity services, which was valuable in its own right and was a prerequisite to greater involvement.

> 'The MSLC is meeting its potential 70:30. The potential is met to an extent in that the MSLC is an information provision and discussion group. The 70% is not met because there is no link, no getting things done.' (User member, MSLC E)

When they were particularly frustrated with the attitudes and behaviour of health care professionals and had doubts that their goals would be realised they began to question whether the MSLC was worthwhile. This happened frequently to some user members.

> [Overall how worthwhile do you think the MSLC is?] 'In the grand scheme of things... there are two ways of looking at it really. In one fell swoop I could say, well what is the point really, but in another, with my other head on, I could say it is definitely worthwhile. The changes need to be made, need to be initiated and the MSLC is a really good way of doing it.' (User member, MSLC D)

Health care professionals

There was variation in the extent to which health care professionals thought their MSLCs were worthwhile. Some were philosophical about the weaknesses and valued the benefits. These tended to be those who were not concerned about the representativeness of user members. They thought there were problems with representation but that this did not negate user members' views altogether. They were interested to hear what users had to say. This position meant that they were able to appreciate the opportunities for multidisciplinary working with their colleagues and to

use the MSLC as a source of support. Most of these respondents were able to identify changes - however small - that the MSLC had promoted in maternity services, but this was not vital to a worthwhile assessment. Community practitioners were particularly receptive to the benefits associated with multidisciplinary working.

> 'I doubt if it makes any significant difference to the outcomes of most of the things discussed. But having said that, I think it's a useful committee because it co-ordinates people taking very different viewpoints.. well, hopefully, in the end, the same viewpoint. They all have their bit to say, so I think it does serve a useful purpose, but the actual outcome at the end, I would say I doubt if it changes policy.' (GP member, MSLC B)

Those who were most critical of user members were least likely to consider the MSLC a worthwhile venture. Their frustration with users' demands made them less open to appreciating other benefits the MSLC could provide. They were less likely than more positive respondents to identify any improvements the MSLC had made to maternity services. However, even those who were extremely negative and frustrated were reluctant to conclude that the MSLC should be disbanded as they thought it was important to listen to what users had to say.

Health authority respondents

There was variation in the extent to which health authority respondents thought the MSLC was worthwhile. Some were so frustrated with the amount of work that they had to do or the behaviour of user members that they questioned the MSLC's overall worth. Sometimes they saw the MSLC as a longwinded way of arriving at a point that they could have reached a lot quicker if they had not involved the MSLC. Respondents at the other extreme were more positive about user involvement and appreciated the MSLC for enabling them to build relationships with health care professionals.

In general, health authority respondents were less convinced than users of the value of their MSLC as an important form of user involvement. They saw themselves as having

an important role in representing the population and promoting services based on proper needs' assessments and evidence based practice. They thought there were other ways of involving users on an ad hoc basis that would be less problematic than the MSLC.

> 'If the MSLC didn't exist, public health and the health authority would still continue to perform its functions in terms of trying to improve quality; in trying to sort out the quality of antenatal screening.. indeed, as part of that we might decide we need a multidisciplinary group with the consumer voice. If that particular group was disbanded, I don't think anything dreadful would happen.' (Public health consultant, MSLC A)

Summary of main points

Members had strong views about their MSLCs - they did not describe their committees in neutral terms. Being a MSLC member was associated with a degree of frustration and potential conflict even if overall the perceived benefits outweighed the problems. That the majority of MSLC members considered their MSLCs worthwhile despite many shortcomings and problems demonstrated either their commitment to the principle of user involvement or how much they themselves benefited from being involved with the MSLC.

Chapter ten:

Assessment of MSLC impact

This chapter identifies the mechanisms by which the MSLCs in this study were able to influence maternity services and the conditions which affected the extent of their impact. It makes an overall assessment of the impact of the study MSLCs and concludes by discussing the extent to which the findings of this study are generalisable to all MSLCs.

Mechanisms of MSLC influence

By drawing together the findings of the observation and interviews, it is possible to identify seven mechanisms by which the MSLCs in the study had the potential to influence maternity services. These reflect what the MSLCs actually accomplished rather than what members or documents said they did or could achieve. The mechanisms are:

- making recommendations and suggestions in relation to specific service or health care developments
- raising issues about quality and providing feedback on services
- educating or informing members and others about maternity services
- providing support for members in their work
- promoting communication between constituent groups
- acting as a central point for the co-ordination of initiatives
- promoting the accountability of health professionals

There was variation between MSLCs in the extent to which they did these things and to what effect. While all the study MSLCs made recommendations or suggestions, raised quality issues, educated or informed, and promoted communication and accountability, only half of them provided support and acted as a central point to co-ordinate initiatives in maternity services. There was also variation in how systematically they engaged in these activities. Table 10.1 gives examples of this variation.

Table 10.1: Range of activity encompassed in each role

MECHANISM	LESS SYSTEMATIC ACTIVITY	MORE SYSTEMATIC ACTIVITY
Making recommendations / suggestions	Members making suggestions for improvements during informal discussion about care	An explicit review of care with written recommendations to a defined audience
Raising quality issues and providing feedback on services	User members describing their own experiences of maternity care	The MSLC running a survey of recent service users for their feedback on the quality of care
Educating or informing	User members find out about services through being present at meetings	User members pass on information to local women; help to produce or disseminate leaflets
Providing support to members in their work	Verbal encouragement	Written endorsement
Promoting communication	Health professionals meet each other at MSLC meetings	Members discuss particular problems with the transfer of patients between aspects of the service
Acting as a co-ordination point	Members discuss progress with projects they are involved with outside the MSLC	MSLC co-ordinates project; progress is discussed and assessed, and plans made
Promoting accountability	Health professionals report informally on their policy and practice	Discussion of results of clinical audit and measures to be taken to improve care

Table 10.2 assesses the impact of the study MSLCs through each of the seven mechanisms and the factors which influenced the extent of their effectiveness. The mechanisms are subsequently described in greater detail.

Table 10.2: The impact of the MSLCs

MECHANISM	IMPACT	CONDITIONS INFLUENCING IMPACT
Making recommendations or suggestions	Variable Not always discernible	• nature of recommendations (cost implications) • location of those receiving them: internal or external to MSLC • attitudes of those receiving them • formality of MSLC input and whether formally consulted
Raising quality issues and providing feedback on services	Focused attention on deficiencies in the service and kept them on the local agenda; gave health professionals feedback about maternity care	• attitudes of professionals • remit of the MSLC and opportunities for members to raise problems
Educating or informing	All members better informed; sometimes this knowledge was passed on beyond MSLC	• whether health professionals see issue as important • networking opportunities and inclinations
Providing support	Provided encouragement and support to members wanting to make changes	• opportunities to discuss initiatives on the MSLC • the inclination of health professionals to use MSLC in this way
Promoting communication	Helped resolve problems Occasionally had negative effects	• size of membership and types of health professionals • opportunities to discuss topics in depth • attitudes and motivation of health professionals
Acting as a co-ordinating point	Opportunities for members to discuss their different perspectives and co-ordinate plans or work	• size of membership and types of health professionals • attendance by health professionals • remit of the MSLC • motivation of health professionals
Promoting accountability	Signified health care should be open to scrutiny	• attendance by health professionals • opportunities for health professionals to make reports • degree of openness

Making recommendations and suggestions in relation to specific service or health care developments

The MSLCs looked at the adequacy of specific aspects of maternity services and made recommendations or suggestions for improvements. Their activity ranged from in

depth and systematic reviews of practice through to unstructured and unplanned discussions.

Some recommendations or suggestions were directed at people outside the MSLC, usually in the health authority or hospital trust. Implementation of unsolicited recommendations, particularly those with cost implications, was limited. However, in cases where health professionals from outside the MSLC had asked the committee for its feedback on plans or proposals, these responses were generally taken on board.

Most MSLC discussions and suggestions focused on aspects of care which were under the control of health professionals who were themselves MSLC members. The MSLC's role in discussing such issues was not often explicitly defined, its contribution was neither planned nor systematic, and anticipated outputs were unclear. Suggestions and recommendations for change were made during discussions which came about because someone had an interest in the topic or had provided a report. The implementation of suggestions and recommendations was dependent upon the commitment of health professionals within or outside the MSLC. While many ideas were taken up and there were changes to both policy and practice, others were neither accepted nor acted upon.

Many MSLCs were trying to promote more systematic and formalised input to planning and monitoring processes such as reviewing service specifications and determining topics for clinical audit. Some committees had increased the amount of information they received in relation to these activities, but they had little if any influence on the decision making going on in trusts and health authorities.

The capacity for MSLCs to make suggestions or recommendations depended on their access to information on policy and practice. They were dependent upon health professionals to provide this. Conducting reviews and making recommendations to external bodies (usually the health authority) required someone with not only the necessarily skills and knowledge of the topic and the health service, but also the willingness to take on the task of co-ordinating the work. Those MSLCs with well engaged health authority representatives were most likely to review practice in a systematic way and make recommendations to external bodies about how services could be developed. MSLCs accountable to hospital trusts did not usually have much input from the health authority and their influence was more limited to services which were under the control of health care professional members of the committee.

Raising quality issues and providing feedback on services

The MSLCs provided opportunities for members to raise issues about quality and to gather and pass on feedback from local users. Some of the quality issues raised were national issues such as low levels of satisfaction with postnatal care and concerns about rising caesarean section rates. Local issues included the lack of user friendly information leaflets on maternity services and shortfalls in provision of parent education. MSLC involvement in this way had the potential to promote a sense that the quality of health care was a shared problem and a shared responsibility. In some cases, the problems raised were ones about which the health professional members of the MSLC had previously been unaware.

Health professionals did not always agree with user members about the significance of these issues and therefore did not take responsibility for tackling them but, at the very least, MSLC interest ensured these topics were kept on the local agenda. The

committees provided opportunities for users to engage with health professionals face to face and this made problems harder to dismiss.

User members were the main route by which the views and problems of local women were fed to the MSLC, although some community health care practitioners such as community midwives and health visitors also reported problems they or their patients experienced with maternity services, and some midwifery managers were required to make reports about complaints.

There were three types of feedback from local users: anecdotal reports of the experiences of individual women; aggregated feedback from a small number of women from sources such as user subgroups and visits to postnatal wards; and the findings of more systematic and potentially more representative activities such as surveys and focus groups. User members were instrumental in promoting all three types of feedback although the input of any individual member was determined by the extent of their contact with local women.

The extent to which user members could raise quality issues or provide feedback from local women depended on the MSLC's remit. All the MSLCs were interested in obtaining collective feedback from questionnaire surveys and user subgroups, but the scope for user members to raise problems reported to them by individual women was much greater in MSLCs accountable to hospital trusts.

Educating / informing members and the wider community about health care policy and practice

Through their involvement with the MSLC, all members became better informed about maternity services, albeit in a rather haphazard way. They became better informed about health care policies and practices and the rationale behind service provision, and

as a consequence gained a greater understanding of the complex influences on the work of health professionals. User members in particular felt that this knowledge enabled them to participate more meaningfully on the MSLC. Health care professionals became more aware of important issues in maternity services and better understood the work of other health care professionals that impinged on their own.

User members formed a bridge between local women and health professionals although there were limits as to how far this extended to sections of the community such as ethnic minority groups and women from deprived backgrounds. User members disseminated information on policies, practices and services through their networks. They also obtained responses from health care professionals to the problems experienced by individual women and passed on this information to the women concerned. This had the potential to help settle grievances before they turned into formal complaints. User members also helped to improve the content and availability of written information for local women, in some cases taking substantial responsibility for its production.

The capacity of the MSLC to educate and inform users and health professionals about maternity services depended on the number of MSLC members. In general, the greater the number of members, the greater the number of contacts between the MSLC and outside constituencies. However, the nature of the contact with the outside was also important. For example, user members who ran antenatal classes and were active members of their local NCT branch had more substantial links with local women than did unaffiliated user members or most CHC representatives. And community professionals had less extensive networks with other health professionals than people working in hospitals.

In some cases the information was not disseminated because the will was not there. For instance, consultant members did not always report MSLC business to other consultants and heads of midwifery did not always inform practising midwives in their units about what was happening on the MSLC.

Providing support

MSLC members sometimes used the MSLC as an independent voice to back initiatives they were planning or managing. The MSLC was a potential ally which could add weight to a cause by providing verbal or written endorsement of a plan or decision. In some cases, the support gained by health professionals was a more personal affair and served to reduce their feelings of isolation in their work rather than to directly influence anyone outside the committee. This support was valued by managers who were trying to implement changes and were encountering resistance from staff. Occasionally, the support provided by MSLCs was more tangible, such as when user members worked with midwives to provide a breast feeding advisory service.

The potential of MSLCs to provide support was highly dependent upon whether or not the committee allowed for detailed discussion of initiatives and the extent to which health professionals looked to the MSLC as a source of support. While professional members of some committees regularly used the MSLC in this way, others never did so.

Promoting communication between constituent groups

The MSLC provided a unique opportunity for people with mutual interests whose opportunities for meeting were otherwise non existent or very limited, to meet and talk.

Community practitioners such as GPs and health visitors work independently and were it not for the MSLC they would not meet each other or other health professionals whose work overlaps with or impinges on their own. For many health care professionals it was also the only opportunity to meet face to face with people from the health authority, or at least the only one free from preoccupations with commissioning or funding issues. In addition, the MSLC enabled lines of communication to be opened up between health professionals and users.

These encounters enabled problems to be discussed from all sides and the feasibility of suggestions to be debated with all the relevant people. This helped to resolve problems or communication difficulties between health professionals more quickly and possibly more effectively than would be achieved by telephone or letter. Where the dialogue was constructive it helped to prevent a "them and us" culture.

However, just as communication between health professionals on the MSLC could be beneficial, it could also be destructive because of opportunities for point scoring and openly assigning blame to others. This was not common, but it did happen on several occasions in a minority of committees. And while the MSLC enabled health professionals and users to develop a mutually respectful dialogue it could also promote antagonism, particularly where health professionals were seen as ignoring users' concerns or user members were seen as overly critical and demanding.

The capacity for MSLCs to promote communication increased with the size of the committee and the number of professional groups represented. It also depended on whether the members took advantage of the opportunities to talk with other members. The extent to which members were able to discuss their work depended on whether the remit of the committee allowed for such discussions.

Providing a central point for the co-ordination of initiatives

MSLC meetings provided members with regular opportunities to discuss initiatives with other potentially interested parties and were a convenient place to co-ordinate work. Even where the main work was carried out elsewhere or the MSLC had no clarified responsibility with regard to a project, the MSLC provided opportunities for relevant stakeholders to put forward and discuss their respective views. The MSLC was useful in that it could provide a consensus among health professionals and convenient as all relevant health professionals were likely to be present. User members were not usually central to this MSLC role, but on some occasions they did help to co-ordinate work. Chairpersons had a role in promoting the MSLC as a point of co-ordination by ensuring that topics were kept on the agenda and their progress regularly discussed.

The capacity of the MSLC to act as a point for co-ordinating projects depended on the committee's membership and remit. The larger the MSLC and the wider the representation of professional groups, the greater the potential to contribute in this way. The extent to which initiatives were discussed depended on whether or not the remit of the MSLC allowed for in such depth discussion. The use of MSLCs for this purpose was dependent on the motivation of health professionals.

Promoting accountability

By virtue of their existence and the fact that health professionals were duty bound to report to them, the MSLCs had a role in promoting the accountability of health professionals. The presence of users was a major factor in promoting this accountability. Through asking questions and seeking information they ensured

policies and practices were open to scrutiny. This was not an explicit aim, but happened by default because whatever information the health care professionals provided about their work was exposed to the scrutiny of other members. MSLCs are the only standing forum where health care is discussed in such detail in the presence of users.

Reports by health professionals about their work usually prompted discussion of the adequacy of policy and practice and led to suggestions being made for how things could be improved. The extent to which any suggestions were taken on board was down to health professionals, but nevertheless, MSLC input had the effect of putting the spotlight upon aspects of health care, exposing problems and "monitoring" progress with developments.

MSLC input to processes which might directly promote accountability was quite limited. A minority of committees regularly received information on clinical audit programmes and summaries of complaints and this had the effect of opening up such information to a wider audience, but there was little evidence of any MSLC input to monitoring these activities. Nevertheless, receiving information on such matters indicated that the MSLC had a legitimate right to know what health professionals were doing to promote the quality of their services and deal with complaints.

The potential for the MSLCs to promote accountability was in proportion to the number of health professionals who turned up to meetings. The ability of one MSLC to promote the accountability of consultants was compromised by their poor attendance or complete absence. The work of these consultants could not therefore be discussed nor scrutinised in their presence. The extent to which health professionals made reports

about their work and the degree to which they were open about problems were also pertinent.

Overall, what influence did the study MSLCs have in maternity services?

The demonstrable direct impact of the MSLCs in this study on maternity services was extremely limited, although there were a few examples of actual changes to specific aspects of care. Arguably their greatest influence was in indirectly promoting collaboration and accountability. The sphere of MSLC influence was largely confined to maternity care provided by or under the control of health professional members. There was little evidence of any influence on any decisions made outside the committee. The MSLCs did provide support and a forum for health professionals to communicate and co-ordinate their work. This reflected the lack of opportunity for these things elsewhere in maternity services.

It is important to acknowledge how facets of the study methodology might have affected the nature of these conclusions. The study did not interview people outside the committee to establish the extent of the MSLCs' impact outside the committee. It was possible in most cases to assess the degree of influence - or lack of it - from discussions on the MSLC and from what was said during the interviews, but interviewing outsiders might have contributed something to understanding why the MSLC did not have an influence. A second potential weakness in the methodology was that the longer term impact of some MSLC activity has not been systematically assessed. The minutes of many MSLCs were received for a year or more after the observation period and provided some information. Reports of some MSLC work in this thesis is out-of-date, but there was no evidence from the minutes of any influence or impact that was not in line with the findings of the study.

The impact of MSLCs on maternity services

To what extent can these findings on the impact of the study MSLCs be regarded as relevant to all MSLCs? In order to ensure the findings would be relevant, the sample of eight committees in the study was chosen to include the variety of structural features thought likely to be important to the functioning and effectiveness of MSLCs. The sample MSLCs covered all the possible accountability arrangements, varied substantially in size, covered rural and urban areas and were from a variety of regions around the country. However, there were two areas where the sample did not cover all possible variations.

With the exception of one MSLC where the co-chair was a consultant obstetrician, the sample did not include any MSLCs which were still chaired by health professionals. The two committees that were chosen to represent this category changed to lay chairship soon after the study began. As there was evidence that this change reflected a general trend around the country it was decided not to address the discrepancy. While the presence of a consultant co-chair in one MSLC meant that the impact of this type of chairperson has been studied to some extent, the influence of a single health professional chairperson has not been established. However, the study has established how health professionals influence the committee in various ways and this provides some indication of the high level of influence such a person might have in the chair.

The study did not set out to study the impact of the two tier system of MSLCs - a set up in some districts where there are committees accountable to hospital trusts and an umbrella committee accountable to the health authority. This arrangement was uncommon at the time the sample was chosen, but seems to be increasing. Two of the

study MSLCs were in districts which developed umbrella committees during the study so it was possible to see the impact on them of having this new committee to relate to. However, the sample did not include an umbrella committee so has not looked at issues in the relationship from their point of view. This is not to say that the findings of the study are not relevant to umbrella committees, just that they have additional features which will affect how they work.

These limitations aside, the study found that despite striking differences in structure the MSLCs shared many mechanisms of influence and were subject to the same kinds of influences - albeit to varying extents. This provides some indication that the findings would be relevant to any MSLC. Of course, there will be new influences on MSLCs that have become relevant since the study, such as the way MSLCs relate to Primary Care Groups, and the impact of these remains unknown.

Chapter eleven:

Assessment of user involvement in MSLCs

This chapters identifies the variables which determined the extent and effectiveness of user involvement in the study MSLCs. The first part looks at the factors that affected how users participated in their MSLCs and the second assesses the scope for user involvement to improve given the fundamental nature of the challenges.

Factors influencing user involvement

Ultimately, the influence of user members is constrained by what impact MSLCs can have on maternity services. The previous chapter has shown that the overall impact of the MSLCs was severely limited. However, there are mechanisms by which MSLCs can have good effects in maternity services and user members can contribute to promoting these. The extent to which user members were able to contribute depended on various aspects of MSLC structure and process, and the attitudes and behaviour of members. A summary of the factors and their impact is provided in Box 11.1. They are described in greater detail below.

Membership

Membership of users

User membership of some MSLCs was at quite a low level. Many committees had meetings at which there were only one or two user members. The smaller the number of user members, the more limited the potential for the MSLC to tap the views of local

Box 11.1: Factors that had an impact on user involvement in MSLCs

FACTOR	PROBLEM	IMPACT
Membership	Users: • shortfalls in user membership • limited networks with local women • recruitment difficulties • professional resistance to increasing user members	• limited representation of users' views at meetings • limited capacity to inform local women
Attendance	• poor attendance by consultants and GPs • poor attendance by a small number of user members	• reduced opportunities for users to find out about policy and practice; to give feed back on their services; or influence their practice • agenda items and MSLC projects held up
Resources	• lack of administrative support	• slowed down committee work • pushed workload onto user chairpersons • no one to help user chairpersons navigate health service structures and processes
	• limited dissemination of published information	• users not adequately briefed for discussions and less confident about taking part
	• restricted reimbursement of user members' costs	• membership only viable for users who can cover costs of childcare • lowers morale of user members who think it reflects lack of interest in user involvement
MSLC remit	• mismatch between remit and users' expectations of their involvement	• users who want to raise problems experienced by local women have limited opportunities to do so on some MSLCs; user members who want to have more systematic input to planning and monitoring services have limited opportunities to do so in others
"Ownership" of MSLC	• health authority has a high degree of influence over some MSLCs	• MSLCs focus on the interests of health authority, rather than of users and health care professionals
Committee procedures	• agendas not compiled to accommodate user topics • MSLC topics not chosen democratically	• limited opportunities for users to raise topics
Access to information	• health care professionals not proactive at providing information and not open about problems • information does not exist in a suitable format for the MSLC	• users not informed about maternity services • prevented from in depth discussion of health care, its problems and possible improvements
Response of health professionals to feedback from users	• health care professionals question the representativeness of individual and collective user feedback • limited in their discussion of individual cases by confidentiality	• problems experienced by users are not investigated

users and to disseminate information on maternity care to a wide audience. Such small numbers of user members cannot be expected to adequately represent the diversity of the local population of users in discussions on the MSLC. The problem was compounded by the variation in the networks user members had with local women.

In some MSLCs there were plans to increase lay membership, but in others health care professionals were resistant to this. Those MSLCs wanting to recruit new user members found it difficult to find interested women, especially those who could represent minority interests. There certainly was no pool of local women keen to join the MSLC. Taking part in the MSLC was a daunting and thankless task for many user members and likely to appeal only to women with a particularly high level of motivation.

Some MSLCs were trying to increase their access to users' views by setting up user subgroups. Local women seemed more willing to take part in subgroups than take on full membership of the MSLC. However, there was a danger that subgroups were being used as a substitute for increasing the user membership of the MSLC. While subgroups provided MSLCs with feedback from local users, they did not give women the same opportunities as MSLC membership to take part in discussions relating to the development of maternity services.

Attendance

Attendance by the majority of consultants and GPs was poor. The fact that a minority of consultants did turn up regularly suggests their attendance was as much a function of their level of commitment as it was of practical problems. The inconsistent attendance of health care professionals delayed projects and led to topics falling by the wayside. The absence of consultants reduced the opportunities for user members to

pass on feedback to do with obstetric or paediatric care, to find out about clinical practice, and to obtain explanations of problems experienced by local women.
A small number of user members were also poor attenders. This was a source of irritation and frustration for other user members. Those with low levels of attendance did not engage with the longer term work of the MSLC.

Resources

Most MSLCs did not have a budget and were therefore dependent upon the health authority or trust to supply them with certain resources. Many of the MSLCs accountable to health authorities had adequate administrative support, but in other committees the chairperson or other members did much of the work preparing papers and co-ordinating MSLC work between meetings. There was a limit to what they could do and this had an impact on what the MSLC could achieve.

The lack of a budget made it difficult, if not impossible, for many MSLCs to disseminate published information to members. Some user members could get access to relevant documents through a user organisation, but such documents were not always easily or immediately available. Without the documents or adequate time to read them, user members did not have the necessary background information or confidence to take part in discussions on the MSLC.

Many user members were out of pocket to some extent in that they paid for childcare, travel and literature. They considered themselves fortunate to be able to stand these costs and recognised that for some women this would not be feasible. They did not make a fuss about this issue; apparently expecting to make sacrifices for the cause of user involvement. Health professionals suggested it might be better if the MSLC did

not make a fuss about it either, lest the health authority or trust realised what it was already spending on the MSLC. Whatever the justifications for furtive arrangements, it was unfortunate that the situation appeared to reflect a lack of commitment to user involvement.

MSLC remit

MSLCs accountable to health authorities usually focused on strategic matters, whereas those accountable to hospital trusts were solely or additionally interested in the operational details of service provision and quality. User members had different motivations for being involved with their MSLCs: some were members because they wanted to be able to raise problems experienced by local women; others were additionally motivated by a desire to be involved in planning and monitoring processes on a more strategic and systematic level. The capacity for members to raise problems was greater on MSLCs accountable to hospital trusts than health authorities. User members were thwarted in meeting their goals when their expectations were not matched by the remit of their MSLC.

"Ownership" of the MSLC

The guidelines describe MSLCs as "independent advisory bodies" that should be formally accountable to health authorities. However, this assumption of independence does not accurately reflect the considerable influence that health authority representatives had on the way that MSLCs accountable to health authorities worked and subsequently on how users participated. The issue is not that people deliberately swayed the work of the MSLC in a manipulative manner, but that they naturally focused on the interests of their organisation or the demands of their jobs. In some of

the committees the health authority representatives guided the MSLC reviews and produced important committee documents. Moreover, some of the lay chairs were appointed by the health authority and looked to the health authority representative for guidance and support. These chairpersons had a more strategic interest in maternity services than many other user chairpersons and worked closely with health authority representatives.

Health authority representatives focused on strategic issues and monitoring the extent to which trusts met overall targets or standards set out in contracts or agreements. They were less interested than many user members in the day to day problems faced by service providers and local women. Encouraged by the NHS Executive guidelines, many MSLCs were trying to develop a more strategic role in maternity services and this, combined with the influence of health authority representatives, limited the opportunities for users to focus on their own interests. On some occasions, users who were actively prevented from discussing operational matters were left wondering why they were on the MSLC.

Committee and decision making procedures

The format of agendas for meetings did not always facilitate the participation of user members as it did that of health professionals. In some MSLCs, health professional members had been allocated regular slots for making reports, whereas user members had to wait until the 'any other business' section at the end of meetings to raise their concerns, by which time other people had started to leave. These factors limited the extent to which users' topics were discussed and actioned. In theory, user members could ask for items to be added to the agenda, but they were prevented from doing this by their own lack of confidence and the attitudes of other members.

There was little democratic process in the way most MSLCs chose their topics. The result was that MSLC topics were chosen by those who were most vocal or those who had most control over the agenda.

Access to information

In order to be able to participate effectively in meetings, user members needed an adequate knowledge of health service structures and processes. Some user members had a good knowledge of the health service and processes such as clinical audit because they had contacts in the health service or because their user organisation provided information. Others had to rely on the explanations and information given by health professionals, and these varied in clarity and comprehensiveness.

To be able to keep local women informed about maternity services and to take part in discussions about local services, user members needed access to information about local policy and practice. There were several factors which influenced how well informed users were. There was variation in how proactive health professionals were at informing the MSLC about policies, practices and relevant initiatives going on in maternity services, and variation in the extent to which they provided a comprehensive picture of health care practices and were open and honest about problems. Where health professionals were not adequately forthcoming with information, user members were reliant on other sources of information and while some knew local health professionals who could keep them informed, many did not. A lack of openness on the part of health professionals about problems in maternity services limited the opportunities user members (and other MSLC members for that matter) had to take part in discussions about how things could be improved.

Health professionals were sometimes reluctant to bring information to the committee because it did not exist in a suitable format and would need re-writing and explaining. For instance, clinical protocols are written for a medically qualified person to understand and act upon, rather than a lay person. In addition, health care professionals were resistant to 'publicising' problems with maternity services which might show them in a poor light.

How health professionals respond to user members' feedback on maternity services

User feedback on services came in the form of anecdotal reports of user members on the problems experienced by individual local women, reports from user subgroups, and the findings of questionnaire surveys, focus groups and visits to postnatal wards. On some occasions when problems were raised, they were discussed and action was taken to investigate or resolve them. On other occasions, the behaviour of health care professionals limited the extent to which problems were discussed and acted upon. Health professionals were sometimes reluctant to discuss the details of individual cases raised by users because of concerns about the confidentiality of women and staff.

Where problems were discussed, the extent to which anything was done depended upon whether or not the health professionals accepted the problem. In some cases they were sceptical about the accuracy of what had been reported. On other occasions, the problem was accepted but its significance minimised and no action was taken. Some topics were highly contentious and demonstrated the different expectations health professionals and user members had of maternity services. For instance, some user members wanted home birth to be portrayed as an acceptable

and safe option whereas many health care professionals were opposed to promoting home birth in this way and did not consider it as safe as hospital birth. In addition, many user members had concerns about rising caesarean rates and wanted to see them reduced, whereas many health care professionals thought there were good reasons for the increase.

Health care professionals' concerns about the representativeness of user members led them to question the significance of issues of quality raised by users and any suggestions they made for how things could be improved. There was a view that user members were overly concerned with fringe interests and did not represent the views or needs of the 'typical' user. Many health professionals felt that they gained a better understanding of what local women wanted from their own day to day contacts in the course of their work.

Health care professionals were critical of the validity of the feedback provided by user members and this led them to be sceptical about its significance. They had concerns about the representativeness of survey findings because response rates were not usually very high and therefore likely to be biased to reporting problems. They set greater store by the results of their own unit's surveys which indicated most women were very satisfied with the care they received. Some health professionals were resistant to seeing qualitative information such as the details of individual cases, the findings of focus groups and responses to open questions in questionnaires as useful feedback on the quality of maternity care. There was a tendency to judge the significance of a problem by its frequency of occurrence rather than its potential use in highlighting problems in the system.

User involvement in MSLCs: scope for improvement?

User members were generally very active on their MSLCs. They acted as a bridge between those inside and those outside the health service by raising issues about quality, giving feedback to health professionals, and passing on information to local people. Through the MSLC, they supported initiatives in maternity services and promoted the accountability of health professionals. However, many factors to do with the structure and process of MSLCs and the way members behaved limited the extent to which user members could influence maternity care. Some of these factors have been reported or touched on in surveys conducted by other researchers. They reported that user respondents found meetings intimidating (Newburn 1992) and lacked confidence to participate effectively (Gready and Newburn 1997; Fletcher et al 1997). Problems with attendance and difficult team dynamics were also mentioned (Gready and Newburn 1997). The present study confirms the existence of these problems and helps to explain why users had problems trying to participate.

The fact that some barriers were not common to all committees indicates there may be some leeway for improvement. Aspects of the structure and procedures of MSLCs may be most amenable to change. User membership could be increased, consultants could be encouraged to attend more regularly, health authorities could be required to give MSLCs a budget, agendas could be restructured to promote equal reporting from all constituent groups, and more democratic ways of identifying MSLC priorities could be adopted. However, in practice the implementation of these apparently straightforward changes is not a simple matter. The NHS Executive guidelines tried to address some of these problems but with little success. Undoubtedly some MSLCs could be improved by management or organisational changes and these could be instituted by members of the MSLCs themselves. However, other improvements would be harder to promote

because they would require changes in the attitudes of those involved and perhaps a change in policy outside the committee.

Many of the factors that influenced user involvement reflect fundamental issues relating to the structure of the health service and the way MSLCs were set up, the high degree of professional control over MSLC activity, and the characteristics of user members. These fundamental barriers reflect the three main challenges to user involvement in the health service described at the end of chapter four. These issues are difficult to address because they are outside the control of user members and sometimes even of the MSLC.

The structure of the health service and the way MSLCs were set up

Paradoxically, despite their multiple links, MSLCs are very isolated organisations. They have been set up in such a way that their activity is not formally interconnected with that of other organisations. User involvement through MSLCs is add-on. Identifying audit priorities, planning new units and surveying users are activities that go on regardless of the MSLC's input and health professionals are not accountable for the extent to which they involve the MSLC.

Much of the policy on MSLCs has focused on the form of the committee rather than its function. MSLCs have been encouraged to look at their membership and accountability arrangements, but changes to these have not led to greater MSLC influence. The sphere of influence of MSLCs - and by association, users - remains vaguely defined beyond that it is 'advisory'. MSLC policy has not placed them in a wider strategy of user involvement and the MSLC *itself* has become the strategy. Cynically, it could be concluded that focusing on structure avoids having to confront the thorny issue of what

influence users should have and how local people should be represented. The problem is that without a clear idea of how users are to be represented through the MSLC and appreciation that membership needs to fit into a wider strategy for user involvement, user members are always open to the charge that they do not adequately represent the diversity of the local population.

To be able to participate effectively on their MSLCs, users require access to information on the quality of services, but the way information on quality is used within the health service mitigates against openness. Information may be used to measure the unit against standards or other units. It is not therefore just about quality improvement. The government has promoted user involvement and openness in the health service but at the same time perpetuates competition and has recently introduced a plan to base financial rewards to trusts on the basis of patients' assessments (HMSO 2000).

The planning and provision of centralised and standardised maternity services to a population within a limited budget requires health professionals to focus on the commonalities between women rather than the differences. There is always going to be a tension between this organisational exigency and the principle that services should accommodate the diverse needs and wants of the local population.

The ad hoc nature of MSLCs and the features of information and organisational goals that mitigate against user involvement are not likely to change. There are no plans to change MSLCs or the way health professionals are accountable for taking on board the input of users. In fact, with power for commissioning shifting from health authorities to primary care trusts, MSLCs may be in an even more weak position. In general, GPs are not interested in maternity care and may not see it as an important priority.

Professional control

Health professionals had a substantial influence on the work of MSLCs and the extent to which users were involved in developing maternity services. They shaped the remit and structure of MSLCs and controlled what resources were available and how users' views were taken on board. As gatekeepers to information about local policy and practice they determined what of this was made available to the MSLC. Government initiatives may lead to an increase in information on effectiveness and national standards of care, but detailed information about local policy and practice is available only through the filter of health professionals. The dependence of MSLCs on the goodwill and commitment of health professionals meant that they were far from being neutral forums where everyone was equal.

User members were sensitive to the need to keep health professionals on board. This influenced what measures they were able to take to improve the MSLC. For example, the resistance of health care professionals to increasing user membership does not necessarily prevent the appointment of new user members, but in practice MSLCs did not want to take the risk of alienating health care professionals, some of whom had a tenuous commitment to the committee in the first place and might vote with their feet. Similar fears also prevented them formally reviewing the membership of consultants with poor attendance records.

The potential for improvement is dependent upon the will of health professionals. The study has shown that many health professionals see user involvement as a mechanism for getting feedback on maternity care (not always welcome at that) rather than for user involvement in decision making. They do not think of MSLCs as places where the views of users should be accommodated and reconciled with their own.

However, the fact that a small minority were more positive and saw benefits to greater user involvement provides some indication that attitudes can change. The commitment of an individual health care professional can make all the difference to whether or not users are heard on the MSLC.

To some extent the greater acceptance of user input is dependent on health professionals becoming more open to scrutiny of their practices and the extent to which they are given incentives for involving users rather than it being seen as something to be done in their spare time. The former may happen slowly over a period of time, but the latter might be facilitated by changes in policy.

Characteristics of users and user members

User involvement through MSLCs is dependent upon the availability of local women willing to take part. The problem is that the pool of local women who could help and who are willing to help is quite small. Potential members are likely to be women who feel able to challenge health professionals and these are likely to be from the educated middle classes. User involvement is time consuming and costs money. User members have to make sacrifices. Effective participation also requires skills and a knowledge of the health service.

The disappearance of CHCs will have an effect on the user membership of MSLCs. They are a main source of user representation and provide members with support and access to documents. Without CHCs, it could become even more difficult to recruit user members.

Perhaps the pool of local women who wish to be involved could be increased if user membership was made more attractive. Any measure would have to address issues of resources and the attitude of other members to users. You can increase the knowledge and skills of women through training and this may help those who are already committed to becoming a member but it will not do much to make the role appear more attractive to others. In that there was little or no intention of spending money on user involvement the likelihood of things improving is small.

Chapter twelve:

Evaluation of user involvement in MSLCs and its wider significance

This final chapter assesses the extent to which MSLCs gave users a meaningful role in decision making and examines the extent to which the findings can be generalised to other forums for user involvement in the health service. The first section looks at the policy expectations of MSLCs with regard to promoting user involvement and analyses the extent to which these were met in practice. The subsequent section draws out the main challenges facing MSLCs and the potential relevance of these to other forums. The extent to which the findings of the study can be generalised beyond MSLCs is then examined in more depth. This is followed by an analysis of whether user inclusion in committees and groups can be considered a worthwhile endeavour given the constraints that have been identified and a discussion of the policy implications of the study findings. The final section sums up the extent of user involvement in the health service and makes some suggestions for research and policy which might help to improve the situation.

The extent of user influence in maternity services through MSLCs

Policy guidance in relation to MSLCs expected them to provide opportunities for users and health professionals to work together to agree procedures and plan and monitor maternity services (Department of Health 1982, 1984, 1993; House of Commons Health Committee 1992; NHS Executive 1996). The NHS Executive guidelines expected MSLCs to consult local people about maternity services, to improve information for local women, and monitor users' views (NHS Executive 1996). These

are aspects of user involvement often associated with consumerism in the health service (Potter 1988). MSLCs were also expected to help implement Changing Childbirth locally which means they were to be concerned about the choices available to local women and the extent to which services were women-centred and gave women control over their care (Department of Health 1993a). Together, these expectations suggest a high level of public participation in decision-making, incorporating elements of all three types of user involvement distinguished by Papadakis and Taylor-Gooby (1987), namely, voice, choice and control (see chapter four). The findings of this study cast some doubt on the capacity of MSLCs to meet these expectations.

The main way users had a voice through MSLCs was with regard to providing feedback on the quality of services. The second form of voice was exercised when user members were given opportunities to comment on practices and initiatives that were under the control of health professionals on the MSLC. In general, however, user members were not consulted formally or systematically in relation to the development of maternity services or the planning and monitoring activities conducted by health authorities and trusts. The comments of user members were only taken on board when the conditions were right, in other words when they corresponded with the views of health professionals or where health professionals wanted to promote new initiatives and were receptive to their input. And the capacity of user members to speak for local users in MSLC discussions about local services was hindered by the fact that they did not represent the diversity of the local population and had difficulty reaching some sections of the community.

In theory, MSLCs could promote choice for users in two ways: by making sure choices were made available in maternity services and by ensuring local women knew of these

choices. In practice, user members had a role with regard to informing women, but had little influence on what choices were made available to women. The capacity for user members to promote choice through MSLCs was limited by the fact that health care professional members did not share the same commitment as user members to offering choices such as home birth or greater involvement in treatment decisions. On the contrary, they were more often concerned that women were given too much information already. Opportunities to influence what choices were offered to women by GPs were constrained by limited access to the local population of GPs through MSLCs.

User members were witnesses to reports and discussions and committee decisions and as such their presence was a symbol of the legitimacy of the public's stake in the health service. Their inclusion as members indicated that they had a right to be present where decisions were made. However, this right to be present did not equate to a right to have an influence. User members tried to have an influence by providing feedback and making suggestions at meetings but in practice they had very little influence over the behaviour of health professionals. It was about users having a symbolic voice rather than any direct influence. As such, it was a very passive form of control.

In chapter four it was concluded that user involvement in the health service has generally fallen towards the professional dominance end of Klein's continuum of user involvement (Klein 1975) and does not reach the upper rungs of Arnstein's ladder of participation associated with users having a degree of power (Arnstein 1969). Klein's continuum runs from professional dominance at one end to consumer dominance at the other, moving from information provision and consultation, through negotiation and participation, to the power of veto. MSLCs are heavily influenced by professional interests and fall towards the professional dominance end of the continuum. They have

a limited role in consultation and information - rungs much lower on Arnstein's ladder of participation than those associated with citizens having any degree of control. They provide opportunities for feedback, but there was little evidence of real negotiation between users and health professionals. User members had little or no influence on how much control health care professionals gave women over their pregnancy and childbirth. This appeared to reflect the lack of commitment to the principles of Changing Childbirth among health care professionals (Audit Commission 1997).

In summary, MSLCs promoted choice, voice or control in very limited ways. Opportunities were shaped by health professionals and can be seen as 'gifts' to user members. The capacity for users to influence maternity services did not therefore meet the expectations of policy rhetoric nor the expectations of user members themselves.

It has been suggested that there is an element of theatre in the way users are consulted in relation to the planning of local services (Milewa 1997). For example, local people have to be consulted but major decisions about service configuration are largely influenced by central directives and the requirements of royal colleges. MSLCs could also be accused of displaying an element of pretence in that their existence can be taken to 'indicate' that users should participate in decisions about maternity services, and MSLCs go through the motions as if this is true, but, in practice, they have little input. As is the case with local service planning, this is partly because of the lack of local flexibility to customise local services, but this study has shown that, even within these constraints, opportunities for user input are not made available.

Challenges faced by MSLCs

In any group which includes users there are likely to be factors to do with structure, management or organisation of the group which have a bearing on how well users are involved and these can be improved to some extent. Changes could be made to develop an environment more conducive to decision making and user involvement. For example, agendas could be restructured to promote equal opportunities for involvement and a fair and open way of identifying priorities and concerns could be implemented. Systematic ways could be found of identifying and obtaining relevant documents. There may be a role for guidelines in helping to consolidate and disseminate learning from studies of user involvement and in transferring this to new forums. In MSLCs, user members saw the national guidelines as an important link with the outside world and with more up-to-date thinking on user involvement. The guidelines were used by users and other members to push for change in an indifferent or hostile environment. However, there are limits to what guidelines can achieve. Progress in implementing the guidelines was mainly in relation to structural features of the group such as increasing the user membership and even in these areas progress was slow or failed to meet the standards in the guidelines. It is likely that there is potential to improve functioning in these areas, but only up to the point at which functioning is affected by more fundamental issues relating to the structure and policies of the health service, the high degree of professional dominance and control over decision-making processes; and the characteristics of users themselves. These will be resistant to change and less amenable to simple interventions. They reflect fundamental features of the health service and therefore have relevance to user involvement beyond MSLCs.

Structure and policies of the health service

In chapter four it was discussed how ad hoc user involvement initiatives have been in relation to management and quality processes going on in the health service. It is only relatively recently that health policy has focused on integrating user involvement into structures concerned with management and clinical governance. However, inclusion in the structure does not necessarily lead to real integration. User involvement is easily marginalised. MSLCs are high level groups concerned with developing maternity services strategy, but many barriers were found to limit the influence of users (see Box 11.1 on page 259). Efforts can be made to ensure users are included as members of important groups, but the reality is that management and quality processes go on regardless of user input and the tendency of health professionals to conceive of user involvement and quality improvement as separate processes reinforces this. Including user members in high level groups which make important decisions is not a guarantee of user involvement. It is based on the simplistic notion that decisions are made solely within the confines of meetings. In reality, health professionals communicate outside meetings about important topics and it is these exchanges which set the parameters of the discussion within meetings. This does not necessarily reflect a deliberate attempt to exclude users, although it can be used in this way.

Sanderson (1999) has written that the 'instrumental rationality' of the health service and the steep hierarchical pyramid of organisational control are at odds with the notion of user empowerment. He observes that, to a large extent, workers are as powerless as users in that health policies such as managerialism instigated to increase efficiency and reduce variation around the country have led to increased central control and there is now little opportunity to pursue local priorities. In the MSLC study, there were insufficient resources to implement Changing Childbirth, and decisions regarding plans

for new maternity units and PFIs were well beyond the control of MSLCs and yet these things were of great relevance to the nature of maternity care locally.

This study has shed some light on the relevance of ownership and territory. It is difficult to promote equality of involvement in structures set up and run by those in the health service. MSLCs were supposed to be 'independent' but were firmly situated within provider units or health authorities (see pages 262-3). The experience of this study is that the owner's interests take prominence (health care professionals or health authority managers) followed by those of the next most powerful interest group. This is not necessarily deliberate, but reflects the wider power relations in the health service. User interests are not fundamentally relevant to professional goals and the structure of the health service reinforces this. In an attempt to give an element of control to users and avoid the agenda being taken over by professional interests, MSLCs were chaired by lay people, but the fact is that the committee was still a sub-committee of either the Trust or health authority and thus the responsibility of a senior health professional member. Professional interests continue to predominate. It is clear that lay chairs can be 'led' in various ways and a number (particularly health authority non-executive directors) were selected for their affiliation to organisational goals rather than because of any knowledge of or experience in user involvement in maternity services. The only form of user involvement which is situated within the public domain is CHCs and the work of user organisations. The new opportunities for user representation within the health service are environments set up and maintained by health professionals. As such, the user member can be seen as a guest on their territory.

Professional dominance

In this study a significant barrier to user involvement was difficulty gaining access to information about services and the practices of health professionals (see pages 236, 264). Some health care professionals were not keen to share documents such as unit guidelines even for information purposes. Why were health care professionals unwilling to share this with users? There was some legitimate concern amongst health professionals that information, such as the results of clinical audits, might be used to criticise them or the service. Most people find it difficult to accept criticism, but it can be argued that the extent of the anger and frustration displayed by some health care professionals was indication of a more fundamental concern to protect their status and professional autonomy.

The sociologist Friedson saw autonomy and control over a body of knowledge as the basis of professional power (Friedson 1970). Haug has argued that professional dominance is being challenged by increasing regulation of the medical profession and by the public's growing access to medical knowledge (Haug 1988). User involvement can be seen as an attack on professional autonomy, but one that is more symbolic than real. In this study, there is evidence that health professionals were angry about the 'outside interference' of user members (see, for example, pages 224-5 and 238). However, user members had little influence on what happened in maternity services and therefore the irritation can be seen as out of proportion with actual influence. It can be argued that health professionals interpreted the mere presence of users and the comments they made as an unacceptable questioning of their own position as experts. In addition, it is possible that professionals working in maternity services are more likely to be on the defensive because user involvement in maternity services has been

characterised by promotion of natural birth and a backlash against the medicalisation of pregnancy and childbirth.

With regard to access to information, the public now has greater access to information about the nature and quality of services, and the findings of research, but the empowerment of user members in groups such as MSLCs is limited by the fact that health professionals continue to be gatekeepers to information about what really happens in practice and as such they still hold the balance of power.

The study found that most health care professionals had low expectations of user involvement (see pages 226, 270). Their commitment to user involvement reflected a sense of duty to listen to what users have to say about the services they have received rather than a desire to see them participate in decisions about the development of services. Many health professionals did not put themselves in a negotiating position and in this way appeared to reserve the right to ignore user feedback if there was a lack of congruence between this and what they believed to be happening in the service (see page 266). They 'pulled up the drawbridge' if expectations went beyond what they intended their involvement to be. It seems that their involvement was limited to providing knowledge and as such they can be seen as taking an expert rather than a stakeholder position. This approach can be contrasted with the behaviour of a minority of health professionals who took a more inquisitive and inclusive approach and sought to identify common ground with user members and resolve problems.

Many health professionals seemed to start from the premise that user representatives are overly demanding, difficult and unconstructive (see pages 206-208, 237). To be accepted by professional members a user member had to be seen to appreciate the professional (dominant) interest or managerial (challenging) interest, rather than the

patient (repressed) view. The more doggedly a user member saw the situation from the patient view, the less acceptable they seemed to be (for example, see page 210). They were accused of not understanding important forces in the health service. The culture is such that user members have to earn acceptance by being agreeable and non-confrontational. On occasion, user members were 'congratulated' for such behaviour. These expectations push user members to behave in a certain way if they want to be accepted by the rest of the group. A potential consequence of pressure to conform is that the 'awkward' voices of user members are silenced.

In chapter four it was described how citizen-led user involvement initiatives are often motivated by humanitarian concerns. This study has shown how people with the best intentions to share their experience and improve services for other people become demonised and written off as selfish, middle class, over-demanding consumers if they do not conform. The study has shown how health professionals and managers consider themselves better placed than user members to understand what patients want (see page 266). Recent government policy has provided support for this view by emphasising how well placed health professionals are to represent the interests of patients (HMSO 2000).

Characteristics of users

The study has demonstrated the difficulty of recruiting user members, especially those from minority backgrounds. It has highlighted the difficulties user members have representing the views of local people and providing adequate feedback to their constituent group. It has shown how user members feel isolated and disempowered. These problems have also been reported in other studies (NHS Executive 1998a; Rigge 1994; Liberati 1997). It would seem likely that some of these problems might be

worse in other areas of health. Recruiting user members proved difficult in MSLCs even though 'patients' are young and healthy, albeit with the responsibility of a new baby. In addition, in maternity services the large number of user organisations provides a ready source of potential recruits.

However, this study highlights the fact that the problem is not just a practical one. Users have to have a particularly high level of motivation and commitment to remain in an environment where they do not feel valued or held in high esteem by others. It is perhaps surprising that the turnover of membership was not more of a problem than it was found to be.

This study also suggests that initiatives aiming to improve user involvement which focus on the characteristics of user members are unlikely to have a great deal of impact on user involvement and could be misguided if they distract attention from the more fundamental problems that exist to do with professional dominance and the way the health service is set up. This is not to say that user members do not benefit from training and support - experience is that they certainly do. This and other studies have found that user members find meetings intimidating and lack the confidence to participate and user members value opportunities to share their experiences with other user members (Newburn 1992; Gready and Newburn 1997; Fletcher et al 1997). Training in specific skills such as critical appraisal has led user members to feel more confident about questioning health care professionals. However, the lesson is that providing support, and increasing levels of confidence and assertiveness alone will not lead to greater involvement and therefore that focusing solely on changing user members is insufficient.

A concern of health professionals in this study (see pages 233-4) and in other areas is that the users involved are not representative or typical of the wider population of patients (NHS Executive 1998a; Smith and Dickson 1998; Florin 2000). This study has shown that such criticism provides a convenient excuse for dismissing what user representatives have to say. This confirms Bould's findings that user members are accused of unrepresentativeness when they challenge dominant interests (Bould 1990). This does not just reflect a desire among those in the health service to avoid listening to users as there seems to be confusion about what user representation is and should be. The expectations of health professionals in this study were that user members should be typical users. However, the idea that there is such a thing as a typical user is at odds with attempts to get various minority interests represented on the committee. This confusion has not been resolved and is likely to occur in new forums where representation has not been adequately defined. Part of what needs to be resolved is the lack of appreciation among health professionals of how anecdotal or qualitative feedback on services can be used to improve services.

Wider relevance of findings

How far the findings with regard to MSLCs have relevance for other forums depends on how comparable maternity services are to other services. Clearly, in some ways, maternity services are a special case. Users of maternity services are not ill, but experiencing a normal life event. Many women expect to be treated as equals by health care professionals and given choices about their care. These expectations go beyond those held by many patients using other services. In addition, there is a long history of consumer lobby in maternity services and this may have acclimatised health professionals to user involvement. Another difference is that health care professionals in this area of care are organised in a unique way. Unlike nurses, midwives have

independent practitioner status and can take full responsibility for the care of their 'patients'. The interests of some midwives have been allied more closely with those of women seeking women-centred care than those of the medical profession. It could be argued that all these factors should make maternity services more conducive to user involvement than other health services.

On the other hand, it could be argued that these factors could promote sensitivities against user involvement. The strident nature of some user organisations and their attacks on the medical profession may have made health care professionals more defensive of their practice and less likely to want to work with user representatives. Conflict between midwives and consultants may make it more difficult promote inter-professional working on MSLCs.

However, while there are differences between maternity services and other services and the effects of these can only be surmised, many of the barriers identified in this study are not just attributable to the special features of maternity services, they apply to any service. Problems arising from aspects of the structure and procedures are not peculiar to MSLCs and could manifest in any group. The historical isolation of users from decision making processes and the nature of health policy are relevant right across the health service, as are the high degree of professional dominance and difficulties gaining access to information on local policy and practice. Low expectations of user involvement are not restricted to those working in maternity services. However, the way these factors have an impact on user involvement in different fields may vary. In some forums and aspects of the health service these factors may cause more problems than were apparent in MSLCs.

The health service can be seen as entering a new phase of user involvement with its focus on increasing the representation of users on groups and committees within its structure (HMSO 2000). User representation in groups is now greater on a national level, for example through their inclusion in research advisory groups and the review teams of the Commission for Health Improvement, and on a local level where users are represented in primary care groups / trusts and hospital and community trusts. In addition, local authorities are to have a role in scrutinising local plans and monitoring quality. This study provides insight into how extensive and fundamental the barriers to user involvement are likely to be within such forums. The new groups are likely to encounter problems that MSLCs have been struggling with for years, many of which have been difficult or impossible to solve.

Is user inclusion in committees and groups a way forward?

Given that this study has found that user members had little direct impact on services and the process of MSLCs was controlled so much by professionals, are such forums a worthwhile endeavour for users? The notion that gathering people with conflicting views around a table will lead in some way to 'user involvement' seems over-optimistic given the power relations and highly bureaucratic nature of the health service. Integrating user involvement with other processes in the health service such as clinical governance is desirable because it provides a way for users to get direct involvement in decision making, but in practice it is fraught with problems. It seems unlikely that head-to-head exchanges in groups and committees can overcome the fundamental power issues and there is the danger that the 'celebration' of the inclusion of users in this way might obscure the essential lack of influence that the public has through this mechanism. In such a climate, campaigning from outside such structures might seem to hold more potential. Action by user organisations outside the structure of the health

service might have a greater ability to impact on the public consciousness and policy than fragmented membership of groups and committees. Such groups can be more proactive according to their own agendas and more easily articulate and gain public awareness of the conflicting views between users and those in the health service.

Perhaps the answer is that both outside campaigning and involvement within the health service are necessary. A charge of tokenism can be levelled at groups such as MSLCs but those involved in MSLCs perceived the endeavour to be worthwhile because of indirect benefits and the ways in which such involvement increases the public accountability of health professionals. In addition, such involvement allows user members to capitalise on any propensity health professionals have to consider the user perspective. Through these benefits progress might be made. Sanderson writes that what is needed is persistence and the consolidation of small wins over a period of time (Sanderson 1999).

Other commentators argue that present developments are unlikely to be sufficient and a more radical change is needed to promote user involvement. For example, Wall advocates looking at the possibility of transferring health care to local authorities to increase democratic accountability (Wall 1997). It seems unlikely that the government would consider such a change given the centralised and bureaucratic nature of the health service. In the absence of such a fundamental shift in the balance of power, persistence and consolidation seems a reasonable way forward.

What are the policy implications of the study?

The extent of professional resistance to user involvement on the ground makes it very difficult to promote user involvement in a top-down way. In this environment, it is likely

that policy could more easily influence the structure than the process of initiatives. A focus on structure is certainly present in recent policy. It is now nearly impossible to find a forum without lay representation. Unfortunately, the experience of this and other studies is that having an adequate structure in place for user involvement is important, but not sufficient in itself to promote user involvement. MSLCs have been tweaked over the years to improve their structure and there is now more than one user representative on each committee, but this has not led to great gains in terms of user influence.

On the one hand, it can be argued that it is not in the gift of policy-makers to control all the relevant factors which have an impact on user involvement. On the ground health professionals have ways of reshaping policy to protect their autonomy. In maternity services government commitment to user interests exists in the form of the Changing Childbirth initiative but progress implementing this has been hindered by a lack of professional commitment. The discussion in chapter four illustrated how hard it has been for governments to gain control over the behaviour of doctors.

On the other hand, the government can be accused of failing to do all in its power to promote user involvement. Government commitment to user involvement appears to be lacking when there are funding implications. In maternity services there was government support for Changing Childbirth only so long as it was cost neutral. Little in the way of extra funding was forthcoming when it was clear the targets could not be met within existing resources. In general, there appears to be little commitment to earmarking resources for user involvement. Therefore, the government could improve the situation by providing more resources. It could also do something to address the motivational factors. Health professionals could be held accountable for the processes and outcomes of user involvement, as they are for other quality initiatives. Rewards

could be linked to the involvement of users. Seed money could be provided for partnership projects between users and health professionals. These moves would signal that there is governmental commitment behind the rhetoric about user involvement.

There is evidence that the government can overcome what seem like insurmountable obstacles when it wishes to implement a controversial policy. For example, medical audit was introduced amidst a sea of medical antagonism, albeit slowly and carefully with respect to professional sensibilities. The introduction of audit was part of the government's drive to promote efficiency and gain more influence over medical activity. But, what would be the benefit to the government of increasing the participation of users? It was discussed in chapter four how government initiatives such as consumerism have been motivated more by a desire to gain control over the behaviour of health care professionals than to promote user involvement. It can be argued that the current government's policy of increasing user representation within forums in the health service reflects governmental desire to promote openness and accountability rather than promote active user participation. It can be said that the role of the user in policy has moved from one of user-as-consumer to one of user-as-witness. The former focused on the individual interests of users and ignored their collective interests and the latter focuses on accountability to the public and openness and may ignore participation. In their classification of public participation activities, Maxwell and Weaver (1984) distinguish between open managerial decision-making and full management participation by public representative. Presently, it seems that the government is promoting the first, but not necessarily the second. Policy rhetoric extols the virtues of patient empowerment and users are to be represented on a variety of committees and groups, but it is not clear whether this form of representation reflects ideas associated with consumerism or a more participative form of involvement.

Policies have focused on promoting membership and avoided the more thorny and politically sensitive question of what representation actually means.

Wall (1996) has written that accountability as a concept attempts to describe some of the obligations which should exist between groups and between individuals in these groups. However, its rhetorical use in politics has often emphasised answerability at the expense of more profound ideas of mutuality and social integration. It can be argued that promoting accountability is what is left when users have little influence on proceedings! This can be seen as a bottom-line type of user involvement where the user member is simply a witness to the goings on in the health service. In this study, user members valued this benefit even when they felt they had little influence on decision-making in their MSLCs.

Given the energy successive governments have put into gaining control over doctors, it seems unlikely that they would wish to develop the public as another powerful interest group. After all, users might make decisions that do not fit in with corporate plans. The political response to the funding problem in the health service has been to find technical solutions and increase central control. Negotiation with users does not fit well with this approach on a national or local basis. The government's plan to abolish CHCs can in part be interpreted as a way of being rid of loud, critical and uncooperative voices. The fact that there is a plan to abolish CHCs - whatever their faults - when it is not known whether users can successfully find a voice in the new forums is a cause for concern.

Conclusion and way forward

Milewa et al have written that although there is a high degree of professional dominance in the health service, there have been positive changes in the attitudes of health professionals towards user involvement such that many health professionals now actively seek users' views and there is an established right that users should be involved (Milewa et al 1999). Biggs has described how boundaries between doctors and patients have become redrawn as both have become more sceptical that experts (such as doctors) have the answer for everything (Biggs 1997). The findings of the present study indicate that practice on the ground lags well behind these presumed developments and does not reflect the political rhetoric about partnerships and public participation. The principle of user involvement in MSLCs was by no means unequivocably established and many health professionals had very limited expectations of what it should entail. Health professionals are expected to show commitment to user involvement and may be more open to listening to users, but there were many occasions in the study where health care professionals considered their own views to be more valid than those of user members.

With regard to ways forward, it is important to monitor and evaluate the impact of new opportunities for user representation within the health service. An empirical appreciation of how the constraints identified in this and other studies manifest in a particular committee or group can be used to inform improvements. However, in addition to this ongoing research there is a pressing need to take account of the knowledge and understanding that has already been obtained through research and experience. There is a growing core of knowledge being built up about the constraints on user involvement and how these might be dealt with and yet forums are still being set up without adequate attention to this. Despite the focus in the health service on

promoting evidence-based practice and policy, policy relating to user involvement has been spectacularly devoid of such consideration.

The present developments in user involvement are based on the principle that users should be represented within structures in the health service - they are not based on an empirical understanding of what happens when users and health professionals are brought together in this context. Practical help for such endeavours is sparse. There are few opportunities for people to share learning and there is a considerable amount of re-designing the wheel. Guidance for those involved in user forums on how to optimise the group's structure, organisation and management and greater acknowledgement of the more fundamental barriers present in the health service would be a potentially useful way of moving forward.

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Appendix A

Interview Guide

Background

How / when did you become involved with the MSLC?

Are you involved in any other projects / work / groups to do with maternity care?
Hprofs: Important initiatives at moment / Are you involved with the Maternity strategy group?

What the MSLC is like and what it is for

If you were handing over to a replacement how would you describe the MSLC to them?
... what would you say it is for?
... how would you describe the meetings?

What is it like being a member from your point of view (as a ...)?

The work of the MSLC

What do you think are the important topics on the MSLC agenda at the moment?

For each topic:
- why important
- how the MSLC is involved (what is it doing)
- how THEY are involved (sufficiently involved?)
- progress
- what is helping / hindering

How well do you think the MSLC is incorporating the views of the different people involved? Any not heard?

Do you think the MSLC is looking at the right topics? (what is missing/inappropriate?)

Impact and evaluation of the MSLC

What - if any - have been the benefits / achievements of the MSLC?

What does it add on top of everything else? Overall, is it worthwhile?

Influences on the MSLC (people, methods, resources, MSLC guidelines)

What, if anything, would you say works well about the MSLC? (what is good)

What does not work so well about the MSLC? Implications?

What might improve your MSLC?... If you could change your MSLC tomorrow, what would you change?

Appendix B

Table I: Number and percentage of members in each constituent group who missed two or more meetings over the observation period (not including absences due to starting or leaving the MSLC)

Group	A	B	C	D	E	F	G	H	All
Users	3 (60%)	1 (50%)	0	3 (60%)	3 (60%)	1 (25%)	2 (22%)	1 (25%)	14 (38%)
Midwives	4 (67%)	1 (17%)	0	1 (25%)	2 (40%)	2 (33%)	1 (25%)	1 (33%)	12 (34%)
Medical	1 (17%)	2 (40%)	2 (100%)	9 (82%)	2 (67%)	2 (50%)	2 (40%)	1 (100%)	21 (57%)
GPs	1 (50%)	0	2 (67%)	2 (100%)	1 (100%)	1 (100%)	1 (100%)	0	8 (62%)
Health visitors	1 (50%)	1 (50%)	1 (50%)	1 (50%)	-	1 (100%)	0	0	5 (36%)
Trust (other)	2 (67%)		1 (100%)	0					3 (43%)
Health authority	1 (34%)	0	1 (50%)	0	0	2 (100%)	0	0	4 (%)
Social services		2 (100%)		1 (100%)					3 (100%)

Table II: Number of new members (N) and members who left (L) in each constituent group in each of the study MSLCs

Group	A	B	C	D	E	F	G	H	All
Users			1N		1L		4N 4L	1N 1L	6N 6L
Midwives	1N	3L			4N 1L	1L	2N 1L	2N	9N 6L
Medical	1N 1L	2N			2N	2N	2N 2L		9N 3L
GPs			1N						1N
Health visitors							1N 1L		1N 1L
Trust (other)	1N 1L			2N 1L					3N 2L
Health authority	1L			1N 1L			1L	2N 2L	3N 5L
Social services									0

Involvement in Health Care Development: Challenges Demonstrated by Maternity Services Liaison Committees

Diane Berrow and Charlotte Humphrey

INTRODUCTION

The inclusion of user representatives in committees and groups is one of several forms of user involvement in the health service. There are several groups that presently include user representatives in their membership, relating to various aspects of the health service. For some years lay members have been included in research ethics committees and in general-practice patient groups. More recently, some of the research advisory groups involved in setting NHS research priorities have included user representatives (NHS Executive Research and Development Directorate 1998) and, at a local level, Primary Care Groups have been required to have lay membership (NHS Executive, 1997).

The inclusion of users in such groups reflects a philosophy of user involvement that users should be involved alongside health professionals in the decision-making process. This contrasts with the degree of user involvement that occurs through most consultation exercises where the user input is separate from where the decisions are made and where the results are fed into the process. The inclusion of users in the research advisory groups and Primary Care Groups provides evidence of the government's commitment to this philosophy at least in principle (NHS Executive, 1998).

However, there have been reports of problems with regard to establishing user involvement in many of the forums. Some Primary Care Groups were found to have delayed the appointment of user members concerned about the dangers of involving an unrepresentative user and what would happen if users identified different and incompatible priorities to themselves (NHS Executive Research and Development Directorate, 1998). User members involved in forums have reported problems with tokenism, isolation and not being taken seriously (NHS Executive Research and Development Directorate, 1998; Rigge 1994; Liberati, 1997).

The danger is that faith in the potential of multidisciplinary structures to provide an effective form of user involvement ignores the very real challenges that face people involved in the process. This chapter draws on the findings of a qualitative study of Maternity Services Liaison Committees – a specific type of user involvement forum – to identify some general challenges to user involvement through multidisciplinary groups. It focuses on five features of the structure and process of MSLCs.

Maternity Services Liaison Committees (MSLCs)

MSLCs were set up in each district in the early 1980s to bring together all the professionals involved in maternity care with lay representatives for the purpose of agreeing procedures and monitoring their effectiveness (Department of Health, 1993). They were set up in response to concern about perinatal mortality rates and the wide variation in these around the country and between social groups (Department of Health, 1982). They have representation from health care professionals who provide maternity care, the health authority and local users. Health care professionals include midwives, consultants, health visitors and general practitioners. Health authority professionals include public health doctors and commissioning managers. Users come from various user organisations including the National Childbirth Trust and Community Health Councils.

MSLCs are interested in the quality and availability of a wide range of maternity services. They contribute to the design of written information for local women about local services, and they are also concerned with wider service developments such as the implementation and evaluation of team midwifery – a way of organising midwives to promote continuity of care. The MSLCs provide an environment where all those involved can discuss progress being made by the unit or health authority in relation to health care initiatives, and one where

In some topics the MSLC has a more central role and coordinates the actual work, for example in reviewing antenatal screening.

There have been a number of initiatives aiming to improve the functioning and effectiveness of MSLCs, many of which were instigated by user organisations such as the National Childbirth Trust, and the focus has been on empowering user members and reducing their isolation (Fletcher, 1996; Cowl, 1997; Key, 1997). Recently there has been a growing emphasis on the importance of team-building and learning research appraisal skills (Crowe, 1997). Participants have found the initiatives useful as a source of support and a chance to find out about the work and problems of other committees. However, there has been little systematic study of the functioning and effectiveness of MSLCs. Information that is available is from questionnaire surveys of MSLC members which were largely restricted to user members. The surveys found widespread concerns about the effectiveness of MSLCs and the extent to which they allow users to participate (Newburn, 1992; Gready and Newburn, 1997; Fletcher *et al.*, 1997). Users reported a lack of confidence in challenging other members and felt that their committees were dominated by health care professionals.

In 1996, in response to concerns about the effectiveness of MSLCs, the NHS Executive launched guidelines for MSLCs which provided detailed suggestions for how they could develop their structure and remit (NHS Executive, 1996). Encouraged by these guidelines, many MSLCs spent time reviewing their own structure and effectiveness, their relationships with the health authority and Trusts, and they have tried to develop more systematic and proactive input to the planning and monitoring of maternity strategy and the development and review of health care policies. Many have increased the amount of information they receive in these areas, but their influence in these matters remains limited or unclear.

METHODOLOGY

The study on which this chapter is based was a qualitative evaluation of the structure, process and impact of MSLCs. It combined longitudinal observation of committee meetings with in- depth interviews to promote understanding of the process of meetings and features of the interaction between users and health professionals. Previous research by others had been limited to questionnaire surveys of understanding of respondents' views in the context of the work of the MSLC and the behaviour of members.

A purposive sample of eight MSLCs was chosen to provide maximum variation on characteristics likely to be relevant to functioning including whether or not they were accountable to the Trust or health authority and the size of the committee. The meetings of the eight committees were observed over a one-year period in order to study how topics progressed over time and to establish how the work of the MSLC linked in with annual commissioning and monitoring activities in the health authority and Trust. An unstructured approach to observation was taken. What was said and what happened at meetings was recorded as comprehensively as possible using shorthand. Impressions of meetings and the behaviour of members were also noted. In total, 34 meetings were observed: between four and six in each MSLC.

Semi-structured interviews were conducted with a cross-section of members in the second half of the observation period. The primary aim of the interviews was to find out about the respondents' experiences of membership and their views on the functioning, effectiveness and value of their committees. Forty people were interviewed: eight user members, seven health authority personnel, 13 hospital-based midwifery managers and consultants, two GPs, one health visitor, one community midwife and eight chairpersons. The observation notes and interview transcripts were analysed by a combination of manual and computer methods.

FINDINGS

The findings in relation to five aspects of MSLCs which had an impact on user involvement are described. These are: user representation, 'ownership' of the MSLC, access to information, how health professionals respond to problems raised by users, and the adequacy of available resources.

User Representation

Membership

The NHS guidelines suggest that user representatives should comprise at least one-third of the membership. Half the MSLCs achieved this

with only one or two user members present. This was due to a low baseline of user membership to start with, poor attendance by some users, or both these factors.

There was evidence of resistance on the part of some health care professionals to increasing the user membership. They had concerns about how representative user members could be and one consultant explained that if new users were recruited, he would feel unable to speak freely at meetings. Those who were committed to appointing more users found it difficult to recruit new members in spite of widespread advertising and the efforts of existing user members to recruit members through their networks with local women. There were particular difficulties recruiting members to represent minority groups. The NHS Executive guidelines suggest existing members can put across the interests of minorities, but the extent to which this is feasible or acceptable is debatable.

It seemed that while many users were interested in describing their experiences to existing user members, most were not willing or able to take part in the MSLC. It was interesting that, despite the fact that they appeared composed and confident, some user members thought meetings were intimidating and found participating nerve-racking. Even those with substantial experience of committees and campaigning described a degree of apprehension in relation to putting forward views that were different to those expressed by health professionals. Some MSLCs had or planned to develop user subgroups where recent users of maternity services met to discuss the care they received and raise problems. User members of the MSLC formed a link between the subgroup and the main committee, and these groups were seen as a way of involving a larger number of women. However, there is a potential hazard if these groups are used as an alternative to user membership. They provide feedback on services but do not promote user involvement in decisions made on the MSLC.

The Diversity of User Members' Interests

In their drive to increase user membership and avoid charges of tokenism, many MSLCs did not take into account the differences in users' interests in maternity services and user involvement. The way they participated in meetings was influenced by these interests. Some were primarily interested in specific aspects of maternity services or in the opportunities to raise problems experienced by local women. Others users to be involved in the planning and monitoring of maternity services on a wider or strategic level.

This distinction between users was not articulated at MSLC meetings and not apparently accommodated in recruitment plans (except in one case where the MSLC had explicitly chosen to recruit a particular non-executive director of the Trust because of her knowledge and experience of the health service). The fact that users who might want to be involved are not an amorphous group and are not necessarily interchangeable is a significant, but unacknowledged issue.

Concerns about the Representativeness of User Members

Some health professionals questioned the representativeness of user members. They were critical that user members only represented fringe interests – those associated with white middle-class National Childbirth Trust members who want natural or home births. They saw users as out of touch with the typical user – the type of user that they should represent. Some health care professionals felt that they gained a good understanding of what local women want from day-to-day contact with them in the course of their own work and considered this to be a more valid source of information on what users want than user members' views. Their reservations led them to doubt the relevance of problems raised by users.

However, the idea that there are typical users can be challenged. Users fall into many subgroups in terms of their needs and wants. Middle-class NCT members might be one subgroup with respect to certain interests; disabled women and teenage mothers might be others. It might be that the planning and provision of centralised and standardised services to a population within a limited budget requires health professionals to focus on the commonalities between women rather than the differences. This demonstrates a potential tension between organisational goals and the multiple and possibly contrasting requirements of various subgroups of users. This was shown in one MSLC when user members pushed for improvements to be made to access for disabled users. Even though some changes were eventually made, the midwife member was quite antagonistic towards the user members as she felt that their narrow focus on disability access demonstrated a lack of appreciation of the wider problems and challenges facing the unit.

Some of the problems to do with representation may reflect the tendency to focus on *form* at the expense of looking at the *function*

of user members they did not discuss this in the context of a wider strategy of user involvement.

'Ownership' of the MSLC: How Independent is Independent?

The guidelines describe MSLCs as 'independent advisory bodies' that should be formally accountable to health authorities. However, there is an issue of how independent these groups are and can be. Most MSLCs were originally chaired by consultants and had little input from the health authority. Most have now changed to lay chairship and have more formalised health authority input and in part these changes were instigated in response to concerns about medical domination of the committees.

The independent nature of MSLCs does not accurately reflect the degree of influence that the health authorities had on the way MSLCs worked and subsequently on how users participated. Some health authority MSLC members were responsible for the MSLC as part of their jobs. In some of the committees the health authority representatives guided the MSLC reviews and took the lead on producing committee documents. Moreover, some of the lay chairs were appointed by the health authority and looked to the health authority representative for advice and support.

Health authority representatives focused on strategic issues. They were interested in monitoring the Trust and less interested than user members in the process of how the units actually meet their targets. Encouraged by the guidelines, many MSLCs were trying to develop a more strategic role in maternity services and this, combined with the influence of health-authority representatives, limited the opportunities for users to raise the problems reported to them by local women. In one MSLC, for example, the health-authority representative explained on several occasions that the problem raised by a user related to an operational matter and therefore did not fall within the remit of the MSLC. While this was in keeping with the new terms of reference of the MSLC, user members were left wondering what they should do and why they were on the MSLC.

The issue is not necessarily that people deliberately swayed the work of the MSLC in a manipulative manner, but that they naturally focused on the interests of their organisation or the demands of their jobs. While the commitment of individuals in the health authority may be critical in ensuring that the MSLC has influence in maternity nised.

Access to Information

User members of MSLCs were reliant on health professionals to inform them about what was going on in maternity services. Without adequate information they could not keep local users informed about policies and practices nor participate effectively or confidently in decisions that related to the planning or monitoring of maternity services. There were several factors which contributed to how well-informed users were.

The Attendance of Health Professionals

Rates of absenteeism for consultants were so high that MSLCs were without consultants at some meetings. The fact that consultants in some MSLCs – albeit a minority did turn up to meetings regularly, provided some indication that the attendance of doctors was as much a function of commitment as it was of convenience. The absence of consultants reduced the opportunities for users to find out about clinical policy and practice and to obtain explanations for problems with obstetric care reported to them by local women. Agenda items and MSLC projects were held up because of a lack of information on clinical practice.

The Extent to which Health Professionals were Proactive

There was variation in how proactive health professionals were about informing MSLC members about relevant initiatives going on in maternity services. For example, while some MSLCs were told about the local audit of the Audit Commission, others were not. The extent to which health care professionals consulted the MSLC for their input to the development or review of health care guidelines also varied and was generally not systematic. Much of the MSLC input to guidelines arose as a consequence of user members requesting this.

The Extent to which Health Professionals were Open about Practices and Problems

There was variation between health care professionals in the extent to which they provided a comprehensive picture of health care practices.

while some provided accounts of practice which showed the problems as well as the progress, others made reports that seemed more like public-relations exercises, skating over any difficulties. For instance, in reporting on progress with promoting breast-feeding, midwives in one MSLC reported great success and provided a wholly positive and trouble-free picture. User members were suspicious because this information did not correspond with what they knew through their own contact with local women and other midwives. The reluctance of health care professionals to provide honest accounts of practice might be due to concern to show the unit in the best light, but it might also reflect a lack of commitment to the MSLC or user involvement.

The Appropriateness of Information for the MSLC

Within the health authority or provider Trust, information is compiled in a format suitable for a specific purpose for instance, clinical protocols are written for the medically qualified person to understand and act upon. Rewriting or explanation might be required for a different audience, and providing such information is dependent upon the time available and commitment of health professionals.

The organisational isolation of MSLCs means that users are dependent upon those inside the health service to bring in information. This is in itself highly dependent upon the commitment of the health care professional to the MSLC. Some user members had their own contacts within the health service from whom they obtained relevant information, but many did not have this facility.

How Health care Professionals Respond to Problems Raised by Users

For some users one of the main motivations for getting involved with the MSLC was to be able to raise problems that they or local women had experienced and see that they are taken seriously by health professionals. A substantial amount of the interaction between users and health care professionals in some MSLCs related to this purpose. Aspects of the behaviour of health care professionals influenced how problems were discussed and acted upon.

Reluctance or Refusal to Discuss the Details of Cases

Health care professionals were sometimes reluctant to discuss the details of problems in relation to individual cases where it might be possible to identify the woman concerned or the staff who provided her care. They did not think it acceptable that individual staff or users might be identifiable and felt there was a danger of this even if the staff or user were not named if the case was sufficiently unusual. They were concerned not to breach their duty of confidentiality to women. In addition, some problems raised by users were the subject of complaints made by users to the provider unit. These were particularly difficult for health care professionals to respond to as they were not at liberty to discuss the details of such cases. They felt they were at an unfair disadvantage – user members could say whatever they wanted, but they could not defend themselves.

The difficulty for MSLCs was how to capitalise on the feedback user members provided while at the same time appreciating the problems from the perspective of health care professionals. The guidance suggests individual case studies could be useful for checking the quality of the service as they provide sufficient detail with which to make an assessment, but this does not accommodate the problems for health professionals.

The Degree to which the Problem is Accepted and Considered Important

Some problems were raised and discussed and action was taken as a result to investigate or resolve them. However, in many other instances the health care professionals did not accept the problem existed or did not consider it necessary to take any action. Comments from health care professionals such as 'That shouldn't happen', or 'That was an atypical experience – most unusual', resulted in a premature end to some discussions. In some cases they were sceptical about the accuracy of what had been reported by the user; in other cases they sought to reassure the user that the policy or practice was adequate. For instance, a user asked for clarification of the Trust's policy on providing scans at night because a local woman had been unable to obtain one. The head of midwifery explained that the policy was to provide scans and the problem should not happen. This kind of reaction had the effect of circumventing a full discussion of the problem to assess if any action needed to be taken. On other occasions the problem was accepted but the significance of it was minimised. The response was that some shortfalls in practice are unavoidable and not worth investigating.

Some user members thought the midwives were deliberately minimising the implications of the problem because of their lack of com-

response to the health care professional's ignorance of what was really happening on the ground midwives on the MSLC were mostly from managerial positions.

From the perspective of health care professionals, the problems raised by users were by their nature critical of the service and sometimes of individual health care professionals. Some health care professionals felt bombarded by criticism. They did not feel that the user members appreciated that the vast majority of women were completely satisfied with the service.

Access to Resources

Most MSLCs did not have a budget and were therefore dependent upon the health authority or provider unit to provide them with certain resources. The lack of money made it difficult to get satisfactory administrative support, limited the dissemination of published information, and restricted what costs could be reimbursed.

Lack of Administrative Support

Members of half the MSLCs found the level of administrative support inadequate. While some had the support of experienced committee administrators from the health authority, others relied upon secretarial support from the provider unit which only provided the service of taking minutes. In some committees, the user chairpersons were doing much of the work preparing papers and coordinating the work between meetings. They explained that there was a limit to what they could do without help and that this had an impact on what the MSLC could achieve. The health authority and provider units reported that there was a general lack of administrative support in their own organisations, and that unfortunately there was none to spare for secondment to the MSLC.

Limited Dissemination of Published Information

The cost of photocopying was absorbed by the health authority or provider unit. However, the lack of a budget made it difficult if not impossible for some MSLCs to disseminate published information to members. There was an expectation that members would get hold of the documents through some other route. Some user members were willing to spend their own money on documents, but such documents were at a disadvantage in discussions as they did not have sufficient background knowledge of the topic area.

Restricted Reimbursement of User Members' Costs

The health authority or provider unit reimbursed travel expenses for users, but there was no provision for crèche facilities or childcare costs. In the absence of a budget, travel expenses had to be claimed retrospectively and the process was in some cases lengthy and bureaucratic. Many user members were out of pocket to some extent, although they considered themselves fortunate to be able to stand these costs and recognised that for some women this would not be feasible. They did not make a fuss about this issue, and seemed to expect to make sacrifices for the cause of user involvement.

When the lack of funds was discussed it was with a degree of resignation that nothing could be done. Health professionals suggested it might be better if the MSLC did not make a fuss about this issue lest the health authority or Trust realised what they already spent on the MSLC. Whatever the justifications for furtive arrangements, it was unfortunate that the situation appeared to reflect a lack of commitment within health authorities and provider units to the MSLC and by implication user involvement. It indicated that health professionals see user involvement as being more for the benefit of the user members rather than for the good of maternity services and therefore not worthy of investment. The fact that some user members were too embarrassed to claim their travel costs reflected this.

CONCLUSION

There are no other groups quite like MSLCs in the health service. However, their experiences are arguably relevant to any groups which bring together health professionals with user representatives, both those concerned with health care such as audit groups and those concerned with planning and development such as Primary Care Groups. Most of the problems are not easily resolvable because they demonstrate some fundamental differences between user representatives and health professionals with regard to what they expect or want from user involvement and show how dependent such groups are on the commitment and behaviour of health professionals. Accommo-

with their task of providing a centralised service. The barriers reflect the way user involvement has developed as an add-on activity within the health service rather than as an integral component of planning and monitoring. User involvement takes place one step removed from the decision-making.

The intention of this chapter has been to provide some insight into the challenges that face such groups and takes the discussion beyond a focus on training-up or empowering user representatives or improving or promoting team-working. The problems experienced by MSLCs demonstrate the extent to which health professionals are in control of health care, have a variety of ways of moderating user input, and are empowered to do this by the structure of the health service and its general approach to user involvement.

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